


HARVARD medicine

WINTER 2020

United in a movement to improve LGBTQ health care



a sense of place

There is a degree of serenity to be found by walking closer to the clouds. Or so it can seem for those traversing the new bridge spanning Longwood Avenue at Blackfan Street. According to MASCO, the nonprofit that provides transportation and other infrastructure services to the Longwood medical area, each weekday between 7 a.m. and 7 p.m. that intersection hosts about 520 buses, 830 cyclists, and nearly 21,000 pedestrians. The bridge, which links to Boston Children's Hospital, was built to help some of those pedestrians avoid the street-level flurry. The solace—and campus view—are simply a bonus.





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FORWARD MOTION: Current students, like Edgar Garcia Saiz, are deeply involved in initiatives that aim to improve how health care is delivered to LGBTQ patients.

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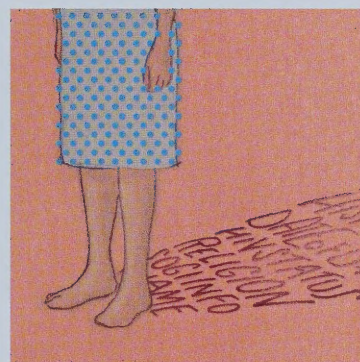
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Alumni recall their thoughts upon first receiving their white coat

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The vital need for better health care for LGBTQ patients



THE HEALTH CARE INEQUITIES faced by sexual and gender minorities cause far too many adverse health conditions: mental health disorders; disproportionate rates of suicide, obesity, and certain cancers; and HIV and other sexually transmitted diseases.

This is unacceptable. Our profession must ensure meaningful improvement in the delivery of LGBTQ health care. I firmly believe that HMS can—and must—lead this widespread change in medicine.

Our commitment to leadership in this area was front and center late last year when the School launched the Sexual and Gender Minorities Health Equity Initiative, a three-

year plan to reshape the core curriculum for our medical students. This farsighted initiative aims to equip our students and faculty clinicians with the training and tools needed to provide high-quality, holistic health care for sexual and gender minority patients of all ages.

As with so many of our curricular changes, we research, we plan, and we innovate—and we also listen to our students. Their interest in ensuring health equity and eliminating health disparities is deep and heartfelt, and their call to ensure that they are prepared to provide competent, sensitive care to these patient populations remains loud and strong.

In 2014, the Association of American Medical Colleges issued a report detailing ways to implement curricular and institutional-climate changes to improve health care for sexual and gender minorities. Jennifer E. Potter, MD '87, an HMS professor of medicine at Beth Israel Deaconess Medical Center and advisory dean of the Castle Society, served on the advisory committee that developed and wrote the report. Potter is also a leader in our faculty cohort addressing these issues through our curriculum. She shares this leadership role with John Dalrymple, MD '91, associate dean for medical education quality improvement at HMS and the Dr. Mark and Karen Lawrence Director of Assessment, Professionalism and Humanism in Medicine, and Alex Keuroghlian, an HMS assistant professor of psychiatry, part-time, and course director for the fourth-year clerkship Care for Patients with Diverse Sexual Orientations and Gender Identities.

In so many ways, our school's initiative is classic HMS. Our students and faculty identify a need, bring their passion and intelligence to bear on finding a solution, rigorously develop and test their innovation, and then bring it forward. I am especially proud that the model curriculum we develop for this initiative will be freely available to any medical school.

We change medicine and, by doing so, we improve the health and well-being of people throughout the world.

George Q. Daley

Dean of Harvard Medical School

Our profession must ensure meaningful improvement in the delivery of LGBTQ health care.

HARVARD medicine

Editor

Ann Marie Menting

Design Director

Paul DiMattia

Associate Editor

Susan Karcz

Designer

Maya Rucinski-Szwec

Contributors

Louise Aronson; Jessica Cerretani; Bobbie Collins; Stephanie Dutchen; Elizabeth Gehrman; Stewart Gilbert; Dominic Hall; Jake Miller; Ekaterina Pesheva

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PHONE: 617-432-7878

EMAIL: harvardmedicine@hms.harvard.edu

MAIL: 107 Ave. Louis Pasteur, Boston, MA 02115

WEB: hms.harvard.edu/magazine

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Care and comfort

Many communities, and many of us in the health care profession, may feel helpless in the face of the strife and struggle occurring at our nation's southern border. We expect that many readers of *Harvard Medicine* do, too. But we also know that communities, including the community of medicine, can and do get involved in supporting those who seek refuge in this country.

According to the 2019 Global Trends report from the United Nations High Commissioner for Refugees, the United States receives the greatest number of first-time asylum applications in the world. Many of those seeking asylum flee their homes because they fear persecution, torture, or even death.

The asylum-seeking population has complex social and medical problems, such as post-traumatic stress disorder; depression; or sequelae of torture, rape, or other forms of abuse. Many face retraumatization during the application process, as they must recall memories that haunt them. The medical and social needs of this population mean that those of us who deliver health care are likely to encounter refugees and asylum seekers in emergency departments and inpatient or ambulatory clinics.

A medical evaluation that documents physical and psychological trauma endured or feared in an asylum seeker's home country can lend vital evidence to an individual's asylum application. Documenting this kind of evidence—for example, characteristic scars from electrocution or flogging or symptoms of post-traumatic stress disorder—can significantly improve a person's chances of being granted asylum. Unfortunately, clinicians who perform such forensic exams are in short supply.

Organizations that help connect lawyers with physicians can be a tremendous aid to asylum seekers. One example is Physicians for Human Rights, a nonprofit national organization that maintains a network of more than 1,500 health professionals who perform these types of forensic evaluations. PHR pairs attorneys representing asylum-seekers with a trained evaluator who then



Young person reportedly seeking asylum in the United States.

provides an informed assessment of any physical and psychological sequelae from abuses suffered.

In addition, there has been a movement within the medical student community to create asylum clinics at their home institutions. Since 2010, when students at Weill Cornell Medical School established an asylum clinic, more than ten U.S. medical schools have set up student-led clinics that support clinician training, facilitate communication between clinicians and attorneys, and provide shadowing opportunities and education for interested medical students.

The Harvard community is part of this movement. In 2016, the HMS student chapter of PHR established the Harvard Student Human Rights Collaborative. One component of the collaborative is a student-run asylum clinic.

The principal aims of HSHRC include using medicine as a platform to raise awareness about human rights violations and advocating on behalf of vulnerable and persecuted people. It collaborates frequently with the Harvard Immigration and Refugee Clinic at Harvard Law School, both on cases and on education and training events. Together with the Massachusetts General Hospi-

tal Asylum Clinic, the law school's HIRC, and the Human Rights and Asylum Clinic, co-founded by J. Wesley Boyd, a psychiatrist at Cambridge Health Alliance, HSHRC hosts an annual asylum evaluation training aimed at expanding the network of trained clinicians available to perform these evaluations.

Our priority as health care professionals is to provide the best individual care possible. To do this for asylum seekers, we need to address their specific needs by providing them interpreters, referring them to asylum lawyers and clinics, connecting them with social workers or patient navigators, and providing them readily accessible resources and education for appropriate social support. We also need to conduct further research to better understand the medical challenges faced by asylum seekers and apply that knowledge to the development and delivery of better care.

If we choose to be even more involved, we can perform pro-bono forensic evaluations, lend our hands at the border, or, in our home communities, work to prevent policies that directly threaten the health of immigrants, such as recent changes to public-charge rules and to medical deferred action. Above all, we should welcome asylum seekers to this country and provide them with the protection and care they need.

INKYU KIM, MEMBER OF THE HMS CLASS OF 2020;
KATHERINE PEELER, HMS INSTRUCTOR
IN PEDIATRICS, BOSTON CHILDREN'S HOSPITAL,
MEDICAL DIRECTOR, HARVARD MEDICAL
SCHOOL ASYLUM CLINIC;
SABRINEH ARDALAN, ASSISTANT CLINICAL
PROFESSOR OF LAW, HARVARD LAW SCHOOL,
ASSISTANT DIRECTOR, HARVARD IMMIGRATION
AND REFUGEE CENTER

Ripple effect

The article "Game Changer" in the Autumn 2019 issue of *Harvard Medicine* told the story of the many institutional changes that Howard Hiatt, MD '48, brought about: changing medicine at Beth Israel Hospital from a profession based on art and anecdote to one based on evidence, and bringing to teaching and research at the Harvard School of Public Health the cutting-edge science and quantitative analytic skills necessary to transform health care delivery in the United States and around the globe. Howard's driving desire to improve our health care system and better the lives of the people it serves has informed almost everything he has done and influenced nearly everyone he has taught during his professional career.

But Howard has done more than transform medical and public health institutions. He has made a difference in the lives of thousands who have received care directly from him and has touched the lives of hundreds of thousands more through the medical students and physicians he has mentored and trained. His mentoring has transformed the lives of three generations of physicians, making them more caring and connected to the people they serve.

Throughout his long and productive career, Howard has nurtured and been a constant source of encouragement for young scientists and practitioners of medicine, especially those interested in public health and the care of the disadvantaged. He has fostered the important work of Partners in Health, a nonprofit committed to bringing the benefits of modern medical science to those living in the poorest areas of developing countries. And, almost twenty years ago, Howard was pivotal to the formation of the Institute for Healthcare Improvement, a leading nonprofit devoted to accelerating the improvement of health care for all, where for many years he served as vice-chair of its board. He also served on the board of The Task Force for Global Health and oversaw its transformation from a tiny nonprofit to one of the largest charitable organizations in the United States. His devotion to this public-spirited effort is typical of his gener-

ous support and encouragement of others in the good work they're doing to improve personal health services.

The success of these organizations and the ability of their leadership to make important changes in health care services worldwide are owed in large part to the mentorship that Howard has provided. Howard would never tell you this, but we, the co-founders of PiH and IHI and president ex-officio of The Task Force, would tell you this many times over.

Hundreds of additional prominent health services researchers, public health advocates, academic medical leaders, and preventive medicine specialists are in debt to Howard for his interest in their development, his support and encouragement through fragile phases of their careers, and his consistent support for novel career paths leading to new collaborations and important new research enterprises. We firmly believe that without Howard's personal attention, today's robust academic fields of decision science, cost-effectiveness analysis, technology assessment, and public policy analysis and planning in health care would be far behind their current state of development.

The importance of a mentor has been described by one of the greatest U.S. authors, Philip Roth. Roth's mentor was his high school English teacher, Bob. Discussing his relationship with Bob in the *New York Times* a few years ago, Roth wrote, "I will put the matter in plain language, directly as I can: I believe we fell in love with each other."

Reading those words and thinking about them many times over, we realize that we, too, have been fortunate to fall in love with an extraordinary mentor. What rare and truly wonderful good luck we have had to develop a lifelong relationship with a mentor like Howard.

DONALD BERWICK, MD '72
BOSTON, MASSACHUSETTS;
PAUL FARMER, MD '88 PhD '90
BOSTON, MASSACHUSETTS;
JIM YONG KIM, MD '86 PhD '93
NEW YORK, NEW YORK;
MARK ROSENBERG, MD '71
ATLANTA, GEORGIA

A transmission electron micrograph showing numerous measles virus particles. The particles are roughly spherical with a distinct outer layer (lipid envelope) and a darker, textured interior (nucleocapsid). They are shown budding from the surface of a cell, which appears as a complex, reddish-brown structure. The background is a light, grainy texture.

Forget Me Not

VACCINATION AGAINST THE MEASLES VIRUS effectively prevents the disease and, according to an international team of researchers led by investigators at HMS, Brigham and Women's Hospital, and the Harvard T.H. Chan School of Public Health, also prevents impairment of immune memory. The research team found that infection by the measles virus wipes out 11 percent to 73 percent of the antibodies that "remember" past infections by other pathogens, making individuals newly vulnerable to a range of other infections—from herpesvirus to pneumonia. The findings underscore the importance of measles vaccination.

Mina MJ et al., *Science*, November 2019

Measles virus particles are shown budding off an infected cell in this colored transmission electron micrograph. As the infectious particles are released from the cell surface, they are enclosed in a lipid envelope (brown edging on particles).

AGING

Neural activity emerges as a factor in longevity

THE BRAIN'S NEURAL ACTIVITY, long implicated in disorders ranging from dementia to epilepsy, also plays a role in human aging and life span, according to research led by geneticists in the Blavatnik Institute at Harvard Medical School.

The study, based on neural activity in humans, mice, and the worm *Caenorhabditis elegans*, suggests that excessive activity in the brain is linked to shorter life spans, while suppressing such overactivity extends life.

The findings, which offer the first evidence that the activity of the nervous system affects human longevity, are intriguing, for they indicate that something as transient as the activity state of neural circuits has far-ranging consequences for physiology and life span.

For this study, neural activity referred to the constant flicker of electrical currents and transmissions in the brain. Excessive activity, or excitation, therefore, could manifest in several ways, from a muscle twitch to a change in mood or thought. The study did not, however, indicate whether or how a person's thoughts or behavior might affect their longevity.

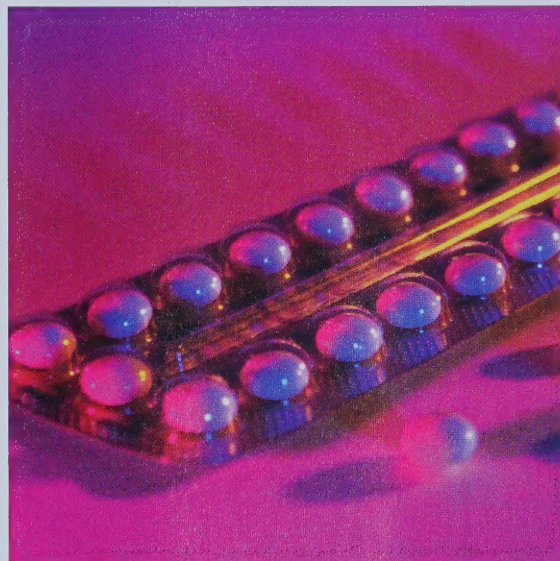
Neural excitation appears to act along a chain of molecular events known to influence longevity: the insulin and insulin-like growth factor signaling pathway. The key in this signaling cascade appears to be a protein called REST. Earlier work on this protein by HMS scientists showed that it protects aging brains from dementia and other stresses.

The findings raise the possibility that certain medicines, such as drugs that target REST, or certain behaviors, such as meditation, could extend life span by modulating neural activity.

Zullo JM et al., *Nature*, October 2019

Health Care Policy

Online oral contraception apps shown to be safe and reliable



Web-based services and digital apps that offer oral contraception appear to be safe and efficient overall, says a study of the birth control prescription services of nine U.S. vendors. The results may quell concerns about the safety and reliability of this growing model of care delivery, which gives individuals online access to treatments for a range of conditions.

Jain T et al., *New England Journal of Medicine*, September 2019

MENTAL HEALTH

Forced change to gender identity linked to suicides

A STUDY OF REPORTS from more than 3,800 U.S. transgender adults has found that recalled exposure to gender identity conversion efforts is associated with adverse mental health outcomes in adulthood, including severe psychological distress, lifetime suicidal ideation, and lifetime suicide attempts.

The analysis, conducted by a team of HMS researchers at McLean Hospital, Massachusetts General Hospital, and Boston Children's Hospital, together with scientists at the Harvard T.H. Chan School of Public Health and The Fenway Institute in Boston, also showed that gender identity

conversion efforts in children under the age of 10 were significantly linked with several measures of suicidality, including lifetime suicide attempts, compared with therapy without conversion efforts.

Moreover, the study's findings showed that transgender people exposed to conversion efforts anytime in their lives had more than double the odds of attempting suicide compared with those who had not experienced efforts by professionals to convert their gender identity from transgender to cisgender. These associations with adverse mental health outcomes held true whether the person conducting the conversion efforts was a secular therapist or a religious adviser.

The researchers were especially troubled to discover that exposure to gender identity conversion efforts during childhood was linked with a fourfold increase in the odds of lifetime suicide attempts. This finding, they say, should be noted by those who continue to advocate for gender identity conversion efforts in young children.

Turban JL et al., *JAMA Psychiatry*, September 2019

CLINICAL MEDICINE

Ear infections may worsen speech perception

CHRONIC CONDUCTIVE HEARING LOSS, which can result from middle-ear infections, may lead to neural deficits that decrease the ability to recognize words, especially in noisy environments, according to a study by HMS scientists at Massachusetts Eye and Ear.

The study results indicate that chronic sound deprivation can lead to speech recognition difficulties consistent with cochlear synaptopathy, also known as hidden hearing loss. To offset this potential outcome, they say, clinicians should consider providing amplification in the management of unilateral conductive hearing loss.

Conductive hearing loss occurs when sound transmission from the ear canal to the inner ear is impaired, leading to a reduction in the perception of sound levels and an inability to hear soft sounds. Sensorineural

hearing loss occurs in the inner ear when the conversion of sound-induced vibrations into electrical signals in the auditory nerve is impaired.

For this study, researchers retrospectively reviewed the hearing profiles of more than 200 patients with either acute or chronic unilateral conductive hearing loss but with normal sensorineural function on hearing tests. Patients with longstanding moderate to moderately severe conductive hearing impairment were found to have lower speech-recognition scores on the affected side than the healthy side, even when the speech was loud enough to be clearly audible.

Middle-ear infections are the most common reason for doctor visits and prescriptions among U.S. children, with about 75 percent experiencing one or more ear infections before age 5. These infections can reoccur and persist for many months, resulting in communication difficulties that can remain after the disease has resolved.

The findings are especially important considering that children with asymmetric hearing loss have higher rates of academic, social, and behavioral difficulties, according to the authors.

Okada M et al., *Ear and Hearing*, September 2019

NEUROBIOLOGY

Football careers linked to cognitive risk

THE NUMBER OF YEARS a professional football player plays the game, as well as the position played, appear to be linked to greater long-term risk for serious cognitive problems such as confusion, memory deficits, and depression and anxiety, say researchers at HMS and the Harvard T.H. Chan School of Public Health. Based on a survey of nearly 3,500 former NFL players, conducted as part of the Football Players Health Study at Harvard University, the HMS and Harvard Chan School investigators found that players with careers of ten seasons or more were twice as likely to report severe cogni-



tive problems compared with those who had played a single season.

Similarly, individuals who played as running backs, linebackers, and on special teams were found to have twice the risk for serious cognitive problems and a 50 percent greater risk for depression and anxiety compared with kickers, punters, and quarterbacks, players who reported the fewest symptoms of concussion.

Overall, nearly one in four players surveyed reported symptoms of anxiety and depression and nearly one in five reported symptoms of both conditions. Although career length influenced the risk for depression, with every five seasons boosting the risk by 9 percent, the number of years played was not linked to greater anxiety risk.

The researchers also found that the age at which an individual began playing organized football did not affect risk, but cautioned that this finding pertains only to former NFL players, not necessarily to the general population.

Roberts AL et al., *The American Journal of Sports Medicine*, August 2019

PEDIATRICS

Youths' sleep patterns can adversely affect health

ADOLESCENT SLEEP TIMING PREFERENCES and patterns should be considered risk factors for obesity and cardiometabolic health, especially for girls, according to a multi-institution research team led by HMS scientists at Massachusetts General Hospital for Children.

Poor quality and short duration of sleep are known to increase obesity and cardiometabolic risk among children. Until now, however, how sleep timing and teens' own preferences for when to sleep and engage in other activities influence these risks has not been as well-studied.

Timing is a vital component of sleep for it influences whether an individual's circadian clock—the internal sleep/wake schedule—is synchronized with the rhythms of their daily activities. Among adolescents, evening preferences and academic demands can result in irregular sleep schedules that may misalign this internal clock.

The researchers found that teenagers who prefer to go to bed late but need to get up early for school had higher waist circumference and greater abdominal fat deposition than those who prefer to go to bed early and get up early. In addition, the scientists observed stronger associations with adiposity in girls than in boys. The reasons for this finding are not fully understood, but the scientists speculate they may include biological and sociocultural influences.

The scientists stressed the importance of consistent sleep-wake patterns seven days a week, to help reduce the risk of obesity and promote cardiometabolic health. They also recommend ways for achieving this, including family- and community-based initiatives that encourage consistency in adolescents' sleep schedules, such as limiting caffeine use and time spent using electronic media, and school-based policies that would allow for later morning start times.

Cespedes Feliciano EM et al., *JAMA Pediatrics*, September 2019

Nobel Moment

ON OCTOBER 7, WILLIAM G. KAELIN JR., the Sidney Farber Professor of Medicine at HMS and Dana-Farber Cancer Institute and senior physician in medicine at Brigham and Women's Hospital, received an early morning call from Sweden. Foggy with sleep, he listened as the caller from the Royal Swedish Academy of Sciences told him he had won the 2019 Nobel Prize in Physiology or Medicine.

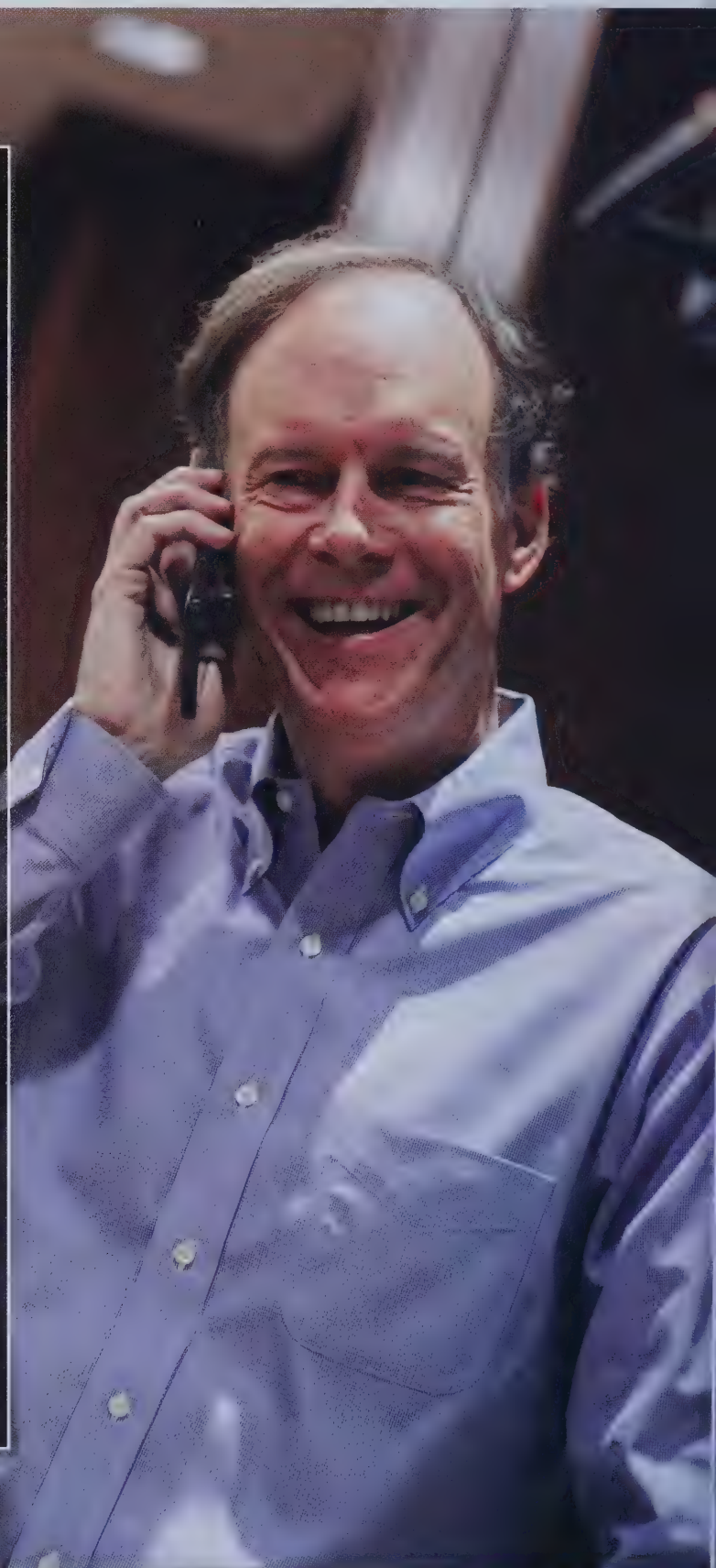
Kaelin shares the award with Peter J. Ratcliffe of the University of Oxford and the Francis Crick Institute and Gregg L. Semenza of the Johns Hopkins University School of Medicine. The trio was cited for the discovery of the pathway by which cells from humans and most animals sense and adapt to changes in oxygen availability, a process essential for survival.

When, in 2001, Kaelin worked out the final details of the mechanism through which cells sense variations in oxygen levels, he said it was very gratifying, as there had been an array of varied, complex theories about how cells sense oxygen.

"When we saw the signal and understood what it meant, it was much simpler than expected," Kaelin said. "We see it conserved across metazoan evolution."

Kaelin's research explores why mutations in genes known as tumor suppressors can lead to cancer. His study of the tumor-suppressor gene *VHL* provided key insights into the body's response to changes in oxygen levels. He discovered that *VHL* helps control the levels of a protein known as HIF-1-alpha, which ratchets up or down the response to low oxygen, by helping spur the production of red blood cells and new blood vessels. His subsequent discovery of a molecular switch that renders HIF-1-alpha oxygen-sensitive was critical to the understanding of how cells react to variations in oxygen level.

This distinguished award joins other recognitions Kaelin has shared with his co-laureates, including the 2016 Lasker Award for Basic Medical Research and the 2010 Canada Gairdner International Award.



noteworthy

A celebration of a 50-year legacy of diversity, inclusion

"The response to this event has been spectacular, heartwarming, even overwhelming," said Nancy Oriol, MD '79, (fig. 1) in her welcome to the hundreds attending the recent celebration marking fifty years since HMS established a program to recruit and support Black students.

To commemorate that historic initiative, alumni and other members of the HMS community gathered to celebrate progress, take stock of remaining challenges, and plan a way forward that would expand diversity and inclusion at the School.

"I am the first to point out that while we are here to celebrate the progress that we have made, we appreciate how much more work there is to be done," said HMS Dean George Q. Daley, MD '91. "It's a responsibility that I, as dean, take extremely seriously."

A highlight of the celebration was acknowledging the contributions of Alvin Poussaint, whose HMS career has run parallel to this fifty-year effort and whose work has been key to making the student body at HMS and the Harvard School of Dental Medicine more representative of the U.S. population.

Poussaint, an HMS professor of psychiatry, emeritus, was recruited following a call, voiced by a group of HMS faculty members inspired by the civil rights movement and spurred by the assassination of Martin Luther King Jr., to have HMS take action to diversify its student body. In 1969, those faculty members, together with one student, presented a proposal to Dean Robert Ebert for increasing the number of "disadvantaged" students at the School.

Throughout the day, speakers emphasized that increasing diversity is not about a single action or metric but is an ongoing process of setting intentions and following through with evaluation, accountability, and continuous improvement.

William Hinton receives long-overdue HMS recognition

A formal portrait of William Augustus Hinton—bacteriologist, author, and social pioneer—was recently unveiled in Gordon

Hall's Waterhouse Room. The event was both a type of homecoming for Hinton, who graduated with honors from HMS in 1912, and a recognition of the power and progress that diversity brings to medicine and the School.

By any measure, Hinton's achievements were remarkable. Born in 1883 to former slaves, he earned a bachelor of science degree at Harvard in 1905, then taught for several years before securing some competitive, prestigious scholarships that allowed him to attend HMS.

Although racism barred Hinton from pursuing a career in surgery at Boston-area hospitals, he was undeterred, becoming a teacher of serology at what was then Harvard's Wassermann Laboratory while also working as a volunteer assistant in the Department of Pathology at Massachusetts General Hospital, where he autopsied individuals who were thought to have died from syphilis.

It was his work investigating syphilis that brought Hinton early recognition as an infectious disease expert. He developed a new blood test for diagnosing the disease, which was adopted by the U.S. Public Health Service, and he wrote a seminal text on the condition, *Syphilis and Its Treatment*. Published in 1936, the book was the first medical textbook written by a Black author to be published in this country.

In 1949, Hinton was appointed clinical professor of bacteriology and immunology, the first Black faculty member to achieve that professorial rank at HMS and Harvard University.

"Professor Hinton was indeed a pioneer," said HMS Dean George Q. Daley, during the portrait ceremony. "He changed the world and made Harvard Medical School a better place in the process."

Hinton also served as assistant director of the Massachusetts Division of Biologic Laboratories and then as chief of the Wasserman Laboratory. Today, the Commonwealth of Massachusetts' state laboratory building is named in Hinton's honor.

The noted scientist and educator also taught at Simmons College, now Simmons University, and established a laboratory technician school open only to women, the first of its kind in the nation.



fig. 1



fig. 2

Medical education leaders learn to navigate changes in the field

An opportunity to rigorously discuss the trends, developments, and current best practices in medical education drew senior academic leaders from twenty-six medical schools around the world who had been invited to attend a three-day symposium convened by the HMS Office for External Education. The ninety participants, representing forty-four institutions, met to consider how to best address the converging forces transforming medical education, including the expansion of knowledge and advancements in biomedical research, the need to train students for delivering increasingly complex levels of patient care, and the promises and challenges presented by new technology.

In remarks to participants, HMS Dean George Q. Daley noted that the gathering, the IMPACT Symposium, brought together academic leaders who sought "solutions to our shared challenges," adding that the event offered all attendees the opportunity "to build a community of like-minded deans and health care leaders working to improve medical education around the world."

The symposium's format allowed participants to work through real-world examples and challenges. There was a session, for example, on how to develop a framework for educators to successfully lead flipped-classroom sessions, led by Richard Schwartzstein, MD '79, the Ellen and Melvin Gordon Professor of Medical Education at Beth Israel Deaconess Medical Center and director of educational scholarship at HMS (fig. 2), and several separate sessions on how to lead faculty through a curriculum overhaul.

David Roberts, MD '95, HMS dean for external education, pointed to the challenges and opportunities that the forces of change were bringing to medical schools globally. Those who participated in the symposium, he said, may be better equipped to help their institutions face those forces, supported in part by their "continued engagement with institutions that share common goals and values."



The care of people with
intersex traits evolves as
clinicians and researchers
learn more, and listen more

The Body, The Self

BY STEPHANIE DUTCHEN

AN OTHERWISE HEALTHY BABY is born with a phallus that seems small for a penis but big for a clitoris. The labia are partially fused so that they resemble a scrotum.

A young girl complains of abdominal tenderness. An exam for a suspected inguinal hernia instead finds a pair of undescended testes.

A teen raised as a male comes to the doctor bleeding from his penis. An ultrasound reveals that a previously undetected uterus has shed its lining through the urethra: he's experiencing his first period.

Each year, a portion of the population is born with biological characteristics—sex chromosomes, gonads, genitalia, hormones, or a combination—that don't fit textbook definitions of male or female. Most differences present at birth. A minority are accompanied by significant, even life-threatening, medical concerns. Others pose little or no danger. In many cases, the physical and psychological risks are uncertain.

Since the 1990s, when patient advocacy groups gained a national platform, debates have churned about which differences indicate pathology and which represent a spectrum of human sex characteristics that deserve acceptance. Such questions have fueled disagreement over whether to refer to

atypical sex characteristics as “disorders of sex development,” or DSDs, as they've been classified by the medical profession since 2006; as “differences of” or “diverse” sex development to avoid pathologizing language; as intersex traits or variations in sex characteristics; or to abandon umbrella categories and use only the names of specific conditions.

It isn't clear how common DSDs are, in part because they encompass some forty to sixty conditions with an even greater number of causes. Estimates of incidence range from more than 1 in 100 to less than 1 in 5,000 births, suggesting a prevalence between 66,000 and 3.3 million people in the United States. For comparison, Down syndrome occurs in 1 in 800 births.

The relative rarity of cases, combined with anemic material in medical school curricula and significant research gaps, leaves many physicians, surgeons, mental health specialists, and others struggling to understand how best to care for these underserved people. Throw in conflicting pressures from professional, patient advocacy, and human rights groups, and the waters grow ever muddier.

Clinical and bioethical questions abound. What's the best way to work with families to assign the “right” sex when babies are born with diverse genital presentations? When and how should health care teams recommend intervening? How do providers act responsibly without a definite diagnosis or long-term outcome data? How to balance safety with patient autonomy? How to uncouple medical necessity from societal pressures that call for people to conform to a sex binary?

It can be hard even to talk about it.

“I think these conditions get stigmatized and compartmentalized because they're sexual,” says psychiatrist Vernon Rosario, PhD '93 MD '95. “We feel like we're supposed to hide DSDs from patients, especially children.”

DSD care is “complicated medically, surgically, politically, and in other ways, and especially recently, it's an area that's been under attack,” says David Diamond, an HMS professor of surgery, the HMS Alan B. Retik Chair and Professor of Pediatric Surgery at Boston Children's Hospital, and a member

of the hospital's Ethics Advisory Committee. "There aren't a lot of colleagues who have the courage to discuss this."

"A lot of clinicians have closed ranks," says Jameson Garland, a Harvard Law School alumnus and researcher at Uppsala University in Sweden, who specializes in children's rights in biomedicine. "They're under incredible scrutiny, incredible pressure to not talk, and many of them struggle to have dialogue outside of their specialty and the medical profession in general."

But avoiding conversation does a disservice to both patients and practitioners, not least because generalists can expect to encounter a handful of patients with DSDs throughout their careers.

"If you practice long enough, you'll definitely come across it," says Vincent Smith, a neonatologist and an HMS assistant professor of pediatrics at Boston Children's. "It helps to think about it and talk about it before it becomes an issue directly related to you, so you don't have to cope with it on the fly."

If anything is clear, it's that the heterogeneity of DSDs reflects a diversity of patient identities and opinions and prevents one-size-fits-all health care decision-making.

Let's talk about sex

Sperm meets egg and chromosomes mix and match. Most embryos inherit two sex chromosomes, either XX or XY, which typically lead to bodies classified as female and male. But the story isn't always so simple. Genetic mutations or variations on the

Avoiding conversation does a disservice to both patients and practitioners because generalists can expect to encounter a handful of patients with DSDs throughout their careers.

sex chromosomes or elsewhere can create discrepancies between the classic karyotypes and physical characteristics. DSDs also can arise if embryos inherit unusual numbers of sex chromosomes, such as X or XXY, or develop different karyotypes in different cells, known as genetic mosaicism. Nongenetic factors contribute as well.

Early fetuses have a structure called the urogenital ridge that gives rise to the gonads, kidneys, and adrenal glands. This interconnectedness explains several DSDs, including why babies with changes in the Wilms' tumor suppressor gene *WT1* have a high risk of kidney failure and tumors in childhood along with underdeveloped gonads and genitourinary variations.

Rarely, gonads fail to develop altogether, leaving nonfunctional streaks of fibrous tissue with high cancer risk. Or, in the second most common cause of diverse

genital presentation, embryos develop one mature gonad, usually a testis, and one streak gonad. In ovotesticular DSD, infants have a mix of gonadal tissue.

In some DSDs, the Wolffian ducts, which usually become the vas deferens, epididymis and seminal vesicles in males and disappear in females, or the Müllerian ducts, which usually become the Fallopian tubes and uterus in females and disappear in males, don't develop as expected. Boys with persistent Müllerian duct syndrome have problems producing or detecting the hormone that normally suppresses maturation of female-associated structures. In girls with Mayer-Rokitansky-Küster-Hauser syndrome, the Müllerian ducts don't form at all.

Many DSDs alter development of the external genitalia, which usually form as clitoris and labia unless exposed to testosterone from the testes.

Vincent Smith



People with XY chromosomes whose bodies can't detect androgens appear female at birth, and at puberty they develop breasts as testosterone gets converted to estrogen, but they don't produce sperm, have a uterus, or develop secondary male sex characteristics.

Inherited enzyme deficiencies can disrupt cortisol production by the adrenal glands, known as classic or severe congenital adrenal hyperplasia (CAH). The glands churn out excess androgens as they try to compensate. In fetuses that are genetically female, this androgen bath virilizes the genitals, sometimes to the extent that they're presumed male at birth. In about 75 percent of cases, the adrenal glands also can't produce hormones that balance salt and water in the kidneys, which, if not treated, can cause fatal complications in the weeks following birth. All fifty states screen newborns for classic CAH. Like insulin for type 1 diabetes, people with CAH need hormone supplements for life. CAH is the most common DSD for people with XX chromosomes.

If a genetic male has trouble converting testosterone to dihydrotestosterone, the urethra, initially located between scrotum and anus, may not reach its destination at the tip of the penis. Research suggests that this condition, hypospadias, affects about 0.4 percent of babies assigned male and is on the rise, likely because of environmental chemical exposure. Such exposure may also be triggering a rise in the incidence of undescended testes. Less commonly, failure of testosterone conversion can lead to diverse

genital presentations in XY babies, who then develop male secondary sex characteristics at puberty when androgens surge.

Many more variations can arise from developmental byways. While effects vary, it's common for people with DSDs to experience infertility or low fertility and to need hormone replacement to induce puberty or carry out other biological processes.

The weight of research

For many infants who present with diverse genitalia, the precise etiology remains unknown. Without a definitive diagnosis, clinicians can't rely on evidence or experience to guide care, says Rosario.

Researchers have unearthed dozens of genes and even more variants that contribute to DSDs. Still, the ever-expanding list explains a mere fraction of physical diversity. Sequencing techniques currently can detect a genetic cause for 20 percent to 45 percent of intersex babies.

Geneticists are trying to change that. At HMS and Boston Children's, a team led by Joel Hirschhorn, MD '95 PhD '95, and Ingrid Holm is conducting whole-exome sequencing of infants with classic DSDs as well as infants with a broader range of variations to illuminate the genetics of sex development and assess how parents respond to test results.

International databases and multi-institutional research networks are making another dent in the unknown. The International DSD Registry hosts data from about 3,000 patients, ranging in age from infancy

Sequencing techniques currently can detect a genetic cause for 20 percent to 45 percent of intersex babies.

to 77 years, in thirty-four countries. The National Institutes of Health-funded DSD Translational Research Network, spanning twelve U.S. clinical sites, is examining genetic causes and participants' physical and mental health.

By centralizing and standardizing data collection, such efforts have begun to identify new DSDs and biomarkers and track short- and long-term outcomes of DSDs and treatments, information that's historically been in short supply, with the goal of improving diagnosis and care. The results also could clarify how often people with DSDs are assigned a sex at birth that they later do not identify with, a rate that studies estimate to be between 5 percent and 60 percent, depending on the condition.

Consensus statements from groups that include physicians, surgeons, bioethicists, lawyers, and patient advocates have attempted to synthesize the slim but growing body of research on DSDs and facilitate agreement on how to proceed. The first, known as the Chicago consensus, was published in 2006 and initiated many of the changes seen in intersex care, including the coining of "disorders of sex development" and a recommendation that patients be assessed by multidisciplinary teams in specialty centers. In 2016, a Global DSD Update revised the Chicago report. Still, gaps remain between recommendations and practice.

Intersex research funding is on the rise, though it has a long way to go. In fiscal year

"The person who has to live with this should have a voice when it's appropriate. If there's a medical indication to not wait, that trumps other things. But all else equal, it's better for the person to contribute."

2017, the NIH funded just eight projects related to DSDs, according to a portfolio analysis by the institutes' Sexual and Gender Minority Research Office. It's a morsel, and hunger is growing.

"When I attend sexual and gender minority research meetings, there are increasing numbers of research scientists interested in exploring this area," says Jennifer E. Potter, MD '87, an HMS professor of medicine at Beth Israel Deaconess Medical Center. "So that's a real positive."

No more simply pink or blue

Medical and surgical practices are evolving as well, both in technique and philosophy. As times change and patients speak up, more practitioners question a tradition in intersex care that reinforces gender binaries and heterosexual norms.

For some people with DSDs, gender identity aligns with the sex they were assigned at birth; for some it does not. Some identify as male or female; some do not. Some are straight; some are not. For many, gender identity and sexuality are complicated.

"We've basically been thinking about sex development and gender identity all wrong for a very long time, and that has done a disservice to an entire population of people who do not fit our traditional expectations," says Potter.

In the 1950s and '60s, influential but now discredited research argued that having "normal"-looking genitalia and a clear gender of rearing would lead to "stable male or female identity" and prevent same-sex

Another mid- to late-century trend now seen as a blunder was a tendency to hide DSD diagnoses.

attraction. The research intensified practices that had begun in the 1920s in which infants with variant or discordant sex characteristics were surgically altered to conform to certain male and female standards, and parents were encouraged to reinforce the assigned gender. Surgeons tended to prioritize fertility for those assigned female and sexual satisfaction for those assigned male. Vaginoplasty was recommended for female-assigned infants not only so those with a uterus could menstruate at puberty but also on the assumption that those with or without a uterus would later want to accommodate penile intercourse. Cosmetic outcomes frequently took precedence over future sexual function and sensation.

Another mid- to late-century trend now seen as a blunder was a tendency for practitioners and parents to hide DSD diagnoses. Patients sometimes didn't discover they were intersex until well into adulthood. Many children weren't told they'd undergone procedures or weren't told why.

Documentation of psychological harm stemming from secrecy, legal requirements for informed consent, and other practical considerations—that patients will eventually grow up and see their medical records, that they will need to manage any related health issues—have led to greater transparency and shared decision-making between doctors and families. The American Psychological Association recommends explaining DSD diagnoses to children "throughout their lives in an age-appropriate manner."

Along with openness has come an increasing emphasis on patient consent and autonomy. Many of the intersex people who have spoken publicly about their experiences express anger and anguish at not having been involved in major decisions about their bodies, especially when procedures resulted in infertility or in altered or "wrong" genitalia. Emotions have run even higher since research and patient testimonies revealed higher than expected rates of surgical complications such as pain, scarring, stenosis, poor sensation or sexual enjoyment, reduced sexual function, incontinence, and other dysfunctions.

Pause, consider

Shifting to a consent-based model translates to postponing medically unnecessary interventions until patients are old enough to weigh in. A key question in intersex care then becomes what to consider unnecessary.

Sometimes distinctions are clear, as with salt-losing CAH, *WT1* mutations, and other serious issues that may accompany diverse genitalia, such as an incomplete urethra or rectum, defects in the heart or other organs, microcephaly, joined fingers, epilepsy, or thalassemia. More often than not, however, the line isn't so sharp.

"Some kids are born with significant midline malformations that require surgery just to survive," says psychiatrist Rosario, who served on a multidisciplinary care team in a children's DSD clinic at UCLA and sees patients through the Los Angeles

"As physicians and as a society, we've evolved, but we're not to the point where we can routinely be comfortable with ambiguity. Some families can take that leap, but they are so uncommon."

County Department of Mental Health. “I don’t think even intersex activists would say you shouldn’t do that. The challenge then is determining what is lifesaving versus what’s more cosmetic. That is a gray area.”

It used to seem clear that surgeons should remove gonads because they carried high risk of becoming cancerous. Then researchers found that malignancy isn’t such a given. As studies narrow down gonadal cancer likelihood and timing for individual DSDs, recommendations have shifted toward active surveillance or watchful waiting to extend fertility and allow natural induction of puberty. Most people with DSDs can now safely retain well-developed gonads until puberty or later if desired, allowing them to participate in decision-making about risks and benefits. For those who do remove gonads because of cancer risk or to avoid initiating puberty in a gender they don’t identify with, doctors may be able to offer fertility preservation options.

Clinicians also are revisiting estimates of the likelihood that being born with a shared exit for the urethra and vagina leads to repeat-

ed urinary tract infections. If the risk proves lower than previously thought, surgeons may be able to delay procedures on this region until patients can have their say.

It’s been standard practice to surgically correct hypospadias. Stakeholders are now asking if the purpose is to allow urine and semen to exit the penis in a “normal” location, must it be done during infancy, or can it wait?

But the eye of the storm swirls around surgery primarily intended to make internal and external structures more definitively male or female.

A say in the matter

Arguments in favor of performing non-urgent, so-called gender-normalizing operations in infancy range from the surgical to the social, including that children won’t remember the procedures, wound healing is faster and bleeding less, children won’t grow up “confused” about their sex or gender, and patients and families won’t be bullied or stigmatized for being different.

“With some of these anatomic disorders, it’s much easier technically to do a surgi-

Over the past decade, advocacy groups have led a global movement calling for a moratorium on genital and gonadal surgeries without patient consent.

cal procedure when a child is little,” says Diamond. “Usually when it’s easier for the surgeon it’s an easier recovery for the patient.”

Those in favor of waiting until patients can participate in decision-making emphasize bodily and reproductive autonomy and the risk of physical and psychological trauma. Surgical complications could overshadow the benefits, they argue. Construction or elimination of genitals could fail to align with the child’s ultimate gender identity. Children are denied the opportunity to say whether atypical genitalia bother them or are just fine.

“Sometimes we get it wrong, and the person who has to live with this should have a voice when it’s appropriate,” says neonatologist Smith. “If there’s a medical indication to not wait, that trumps other things. But all else equal, it’s better for the person to contribute.”

Without long-term outcome data, the risks of individual procedures can’t be quantified, nor can the advantages of waiting versus intervening early. It’s also unclear whether patients who’ve gone public reflect most intersex people’s experiences. Clinicians don’t know how much of the reported distress arises from outdated surgical techniques, nor do they know yet whether current procedures will prove any better.

Researchers are attempting to better gauge outcomes and satisfaction rates. A forthcoming European report will describe the opinions of more than one thousand intersex patients and their doctors regard-



ing satisfaction with “anatomical and functional results of genital surgery,” according to a 2019 review article in the *Journal of Pediatric Urology*. Institutions are conducting other retrospective and prospective studies, such as a U.S. endeavor at multiple sites, including HMS.

Clinicians also are turning to transgender patients for insight. Teens and adults can provide immediate feedback on medical and surgical procedures and describe broad ranges of desired outcomes, which can then inform intersex care, says surgeon Diamond. The relationship seems fitting, since certain surgical interventions for transgender affirmation were informed by procedures developed for infants with DSDs.

But for many intersex advocates, the wait is too long for the results of such endeavors. Over the past decade, advocacy groups have led a global movement calling for a moratorium on genital and gonadal surgeries without patient consent. International health and human rights organizations, including the United Nations and the World Health Organization, have condemned the procedures, and several countries have restricted them. In February, the European Parliament urged member states to prohibit nonconsensual sex-normalizing surgeries “as soon as possible.” Some medical societies, consortia, and prominent figures such as a trio of former U.S. surgeons general have echoed the call. Several states, such as California, have considered bans.

This sea change has evoked an array of reactions, even among patients. People with CAH in particular say that an outright ban will do more harm than good by depriving families of the option to choose surgery. Appending an objection to a 2019 consensus paper by German academics that supported a ban, one CAH group said the majority of those with CAH who identify as female are satisfied with the results of their feminizing surgery and glad to have completed it in infancy.

The idea that the bodily autonomy of intersex children supersedes parents’ traditional roles as health care proxies remains a point of contention. National medical ethics councils in Finland, Germany, Sweden, and

In 2017, parents sued two South Carolina hospitals and a social services department for having performed feminizing surgery on a child they later adopted who grew up to identify as male.

Switzerland say parents cannot authorize medically unnecessary surgery on genitals or gonads; the 2016 Global DSD Update says they can. Though the United States has not ruled on DSDs, its law and culture generally side with parents’ right to choose, say Garland and Diamond, and many clinicians continue to defer to them on intersex care.

“When we discuss the pros and cons of surgery with the family and they say, ‘We understand the different ways to go and this is what we think is best for our child,’ I accept that that is a responsible way to manage the child,” says Diamond.

Some clinicians fear losing the ability to use their medical expertise to guide families and make decisions based on individual cases. “It is not logical to impose mandatory restrictions on surgery in an area as complicated as this,” reads a 2017 joint statement from seven U.S. urology and endocrinology societies.

Rosario served as chair of the medical advisory board for the Intersex Society of North America from 2002 to 2006 before

he joined the UCLA DSD clinic. Initially against infant genital-normalizing surgery, he found that “my opinion softened with actual clinical experience,” he says.

Arguments roil about where gender-normalizing surgery falls along the spectrum of acts performed on infant genitalia. All fifty U.S. states condemn female genital mutilation, some advocates point out, so why should intersex surgery be considered differently? Others make comparisons to male circumcision, yet that practice also has been questioned. Professional societies are increasingly supporting interventions for transgender patients, so why deny the choice to those with DSDs, people ask?

While individual clinicians may support restricting infant genital-normalizing surgery, Garland wonders whether the threat of malpractice litigation explains why the U.S. medical profession tends to emphasize following the standard of care rather than trying nonintervention. He adds that in countries where “the law requires scientific evidence and careful testing to establish the safety and efficacy of medical interventions, it’s been determined that these surgeries clearly don’t meet that standard.”

Pressure to change may come from peers, such as the Massachusetts Medical Society, which is debating a recommendation to delay surgeries on infants with DSDs “that are of a non-emergent status until the individual has the capacity to participate in the decision.” Doctors listen to other doctors, points out Smith, who serves on the LGBTQ committee that submitted the proposal.

Lawsuits also could influence U.S. medical practice. In a case that settled out of court in 2017, parents sued two South Carolina hospitals and a social services department for having performed feminizing surgery on a child they later adopted who grew up to identify as male.

Should DSD care shift, “we will need a new way of thinking about how to determine when a child is able to consent,” says Garland.

Those who worry about the lack of comparative data between early, delayed, and no intervention may take note as more nations and institutions restrict surgery on minors.

“We may have our control group developing in Europe,” says Diamond.

Vernon Rosario



As more practitioners view forgoing surgery as an option, they turn to more flexible alternatives meant to support patients' gender expression, such as hormone treatments. Surgeons also consider middle-ground procedures that preserve gender options as children grow.

In a 2018 case review in the *Journal of Pediatric Urology*, Diamond and colleagues described three infants with genetic mosaicism and complex urogenital and gonadal features whose parents all opted, among other procedures, to create vaginas but preserve the phalluses while they waited for their children to develop a gender. Two families were tentatively raising their children female; the other, gender neutral.

"I wouldn't have thought that way at all ten years ago," says Diamond, who estimates he sees one hundred DSD patients a year in the Behavioral Health, Endocrinology, Urology (BE-U) program at Boston Children's. "My frame of mind would have been that the surgical options were more of a binary choice."

To those who believe that refraining from intervention does the least harm, Diamond says, "You do your best, and you do it with a lot of humility because you know that no matter what you do, as much data as you have, you may be wrong."

Mind and body

Clinicians continue to learn how to avoid inadvertently making things worse for people with DSDs. Research studies and patient advocacy reports have documented the long-term psychological harm stemming from health care experiences such as repeated genital examinations and photography, depersonalization, and demeaning language.

That's part of why psychologists and social workers have become essential members of DSD care teams over the past 20 years, although experts agree that psychosocial care still isn't available to enough families.

"Surgeons and other specialists focus on their areas, particularly on the genitals, and they don't pay as much attention to the rest of the person," says Rosario. "My job is to

ask, how are you doing in school, and how are you doing with friends?"

Although there is variation across conditions, initial research suggests that people with DSDs are more prone than the general population to mental health problems, including depression, anxiety, suicidal ideation, post-traumatic stress disorder, and trouble with intimacy. Such disparities may arise from treatment, culture, or the biology of the DSDs themselves.

Other studies assess the frequency, severity, and nature of parental distress when children receive DSD diagnoses. Researchers at HMS and elsewhere have found that unexpected anatomical variations, the possibility of stigma, and lack of clarity about the child's cancer risk, fertility, and future gender identity can cause significant anguish. Yet they also have found that caregivers of intersex children are no more depressed and, in fact, are less anxious than the general population.

Still more questions center on what should be done if the bulk of distress over DSDs arises from societal rather than medical issues.

Breaking away

In an era of gender-reveal parties and bathroom access controversies, having a "perfectly happy" baby with DSD "can be like a crisis for families," says Smith. "If there are no accompanying medical issues, then it becomes an entirely social-driven crisis."

Clinicians and parents often cite the desire to protect children from social harm when they opt for gender-normalizing procedures. Why, critics ask, in a culture built around binary sex, is the standard solution to alter bodies that are nonbinary rather than broaden societal conceptions of sex and gender?

"It's really fraught when a concerned parent or physician thinks that a child who is intersex, and maybe doesn't present in a typical manner, is therefore going to have a harder time in the world," says Potter. "That might be true, it might not be true, but in any event, trying to 'fix' it so that they look like people with binary bodies may make a big mess of things."

The sharing of people's preferred pronouns, encompassing a spectrum of identities beyond "he/his" and "she/hers," is becoming more common.

"Maybe we should be trying to help parents, and by extension the people surrounding the parents—the extended family, the school system, all of these places—become more knowledgeable that there's a spectrum of sex presentation," she adds. "Instead of conforming a child to something, transform the world in which they live. Then life may not be so hard."

"That's where law can also play a significant role, stopping discrimination and encouraging increased support for parents and children," says Garland.

While Garland, Potter, and others envision a more DSD-friendly future, they acknowledge that the systemic changes required will take time and effort. Meanwhile, others point out, clinicians, patients, and families must live in today's cultural contexts.

Discomfort with atypical sex characteristics "is very much a societal problem, but we are caring for human beings who are brought up in our society to think in certain ways," says Diamond. "As physicians and as a society, we've evolved a great deal, but we're not at the point, I think, where we can routinely be comfortable with ambiguity. Some families can take that leap, but they are so uncommon."

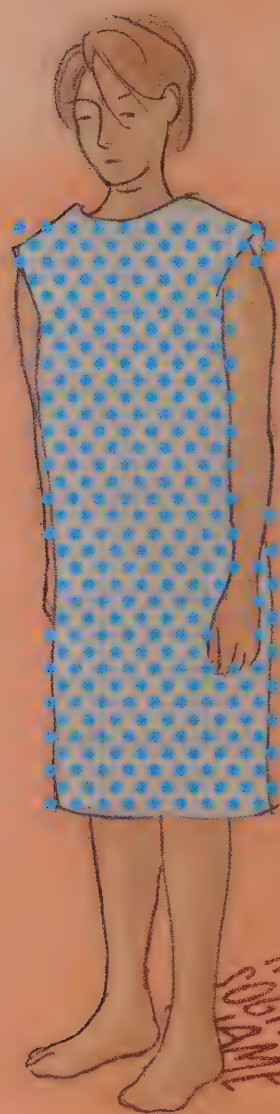
As our culture progresses, that balance may shift. The sharing of people's preferred pronouns, encompassing a spectrum of identities beyond "he/his" and "she/hers," is becoming more common. People with transgender, gender nonconforming, nonbinary, and intersex identities are increasingly out and proud.

"I've been very surprised and pleased to see how much has changed in the LGBT arena in the past twenty years," says Garland. "It's dramatic worldwide. Acceptance has increased of people with different sexualities and genders."

If trends continue, then in another generation or two, the agitation around DSDs may calm. Doctors may deliver healthy intersex babies and simply say: "Congratulations." ■

Stephanie Dutchen is a science writer in the HMS Office of Communications and External Relations.

Gathering a patient's health history is a key first step in the delivery of quality care, but LGBTQ patients may worry about the potential costs of sharing what they've long held close



The Data Trail

BY ELIZABETH GEHRMAN

FROM A MEDICAL PERSPECTIVE, it seems like a no-brainer. “Someone’s sexual orientation and gender identity are a core part of who they are,” says Mark Schuster, MD ’88, founding dean and CEO of the Kaiser Permanente Bernard J. Tyson School of Medicine. “Clinicians should care for the whole patient and should make an effort to understand each patient in the context of their own life.” But for some LGBTQ patients, disclosing information about such matters to health professionals is considerably less straightforward.

Schuster understands both sides of this complicated issue better than most physicians. In remarks he delivered in 2010 at what was then Children’s Hospital Boston, and published in 2012 in *Academic Pediatrics*, Schuster described speaking at his bar mitzvah a few decades earlier, recalling that he had thought to himself, “I am a homosexual standing in front of all these people.” He realized that speaking the words out loud would have been unacceptable in his home, his school, or any place he knew, adding that he “could not have conceived” of telling his doctor. “The idea that I would someday be able to stand in an auditorium, stand anywhere” as an openly gay man, “was not something I could imagine.”

Society in general has come a long way since then, and medicine along with it. But judging from recent research, much more remains to be done before everyone feels welcome in doctors’ offices. A 2015 study in the *American Journal of Public Health* found that LGBT study participants aged 18 to 59 had nondisclosure rates of almost 40 percent among bisexual men, with gay men and lesbians choosing not to share their sexual orientation with their physician at rates of 10 percent and nearly 13 percent, respectively.

This reticence can have serious implications for care. Yet the effort and risk required to discuss what may be a very personal matter can be daunting given the history of prejudicial treatment toward sexual and gender minorities.

“Every time you see a new doctor or nurse,” says Schuster, “you wonder what the reaction will be and worry about the quality of your care. Will you be discriminated against when you’re sick or sitting in a clinical gown feeling very exposed?”

Transgender patients are even more likely to protect their privacy. According to a Trevor Project study released in 2019, only 29 percent of 13- to 24-year-old trans youth or youths with nonbinary bodies disclosed their gender identity to doctors or other health care professionals. A 2015 survey published by the National Center for Transgender Equality helps explain why: 15 percent of trans respondents reported being asked invasive questions unrelated to their visit, 6 percent said they were verbally harassed in a health care setting, 3 percent were refused care, and 3 percent encountered a health care provider who was “physically rough or abusive when treating them” or who physically assaulted them. Sexual assault, too, was reported by 1 percent of respondents.

“There’s no reason not to disclose that you are transgender to someone who’s going to treat you respectfully,” says Jamison Green, a trans author, educator, and activist. “But the problem is we have too much collective experience, and we share the stories in private of being harassed, laughed at, and in some cases, physically struck by people in doctors’ offices. It makes people anxious to know they might be treated insensitively.”

Research has shown LGBTQ people face significant health disparities, and anecdotal evidence abounds that trans people in particular often fail to get the care they need, because of either their own fears or the negligence of health professionals.

“I can tell you hundreds of stories where folks were mistreated, made fun of, or made to feel disgusting or freakish by people who

15 percent of trans respondents reported being asked invasive questions unrelated to their visit.



Cecil Webster Jr.

were supposed to help them,” says lawyer M. Dru Levasseur, deputy program officer at the National LGBT Bar Association.

Careful decisions

The consequences of such closely guarded privacy can be minor—or disastrous.

“It may not always be obvious that being transgender is important to one’s care,” says

Schuster, “but it can be relevant to every specialty.” He cites the example of hematocrit levels, which measure the ratio of red blood cells to total blood volume and can be affected by hormone levels. And while parts of the body like the feet and heart may seem to operate without regard to sexual orientation and gender identity (SOGI) status, a podiatrist who knows a patient’s birth sex

“If a child worries that parents will have access to medical records that reveal something that could cause discomfort, they may choose not to reveal that to physicians.”

or hormone status may be more likely to correctly diagnose osteoporosis or a cardiologist may interpret a trans person's stress test or EKG differently than they would a cisgendered person's. Scientists are just beginning to learn about so many metabolic subtleties in a variety of fields, and SOGI status can add another layer of challenge to getting it right.

Often more immediate and more pressing concerns include the health risks of hormone therapy, including stroke, heart attack, and liver damage in transgender individuals; higher rates of substance use and attempted suicide in LGBTQ adults; and increased homelessness and suicide attempts in LGBTQ youth. The list of health-related differences goes on, leaving some patients feeling like they're caught between two impossible choices: telling and risking embarrassment or worse, or not telling and getting less-than-optimal treatment.

Of course, the two are not mutually exclusive, since disclosure doesn't always guarantee improved care. Levasseur mentions the case of Robert Eads, a Georgia man who began transitioning in his forties and was refused treatment by more than a dozen doctors after receiving a diagnosis of ovarian cancer in 1996. He died three years later, at age 53.

For many trans people, the pain of Eads' story, told in the 2001 documentary *Southern Comfort*, and stories like it, lingers, in part because even though acceptance has grown in the past decade, in many ways U.S. law has not caught up.

The list of health-related differences goes on, leaving some patients feeling like they're caught between impossible choices.

"There's fear around the potential ways health information could be used," says Sari Reisner, an assistant professor at the Harvard T.H. Chan School of Public Health and a research scientist at The Fenway Institute in Boston, where he leads a national and global portfolio of transgender health research. "If information gets into the wrong hands, it could lead to devastating consequences, both on a personal level and for the LGBTQ community."

Health records have different layers of privacy protection. "There are things young people can keep private, for example," says Cecil Webster Jr., an HMS lecturer on psychiatry, part-time, at McLean Hospital and a Boston psychiatrist in private practice. Webster completed his fellowship in child and adolescent psychiatry at Cambridge Health Alliance in 2013. "However, if a child worries that parents will have access to medical records that reveal something that could cause discomfort or even endanger the child's life, they may choose not to reveal that to physicians."

There are other reasons many patients feel, with some justification, that it's reasonable to be cautious.

For now, federal antidiscrimination laws protect health insurance under the Affordable Care Act, but that could change as the current administration seeks to allow providers to refuse coverage or treatment to individuals whose needs may somehow conflict with the providers' self-described religious beliefs. In March of last year, the

administration also reinstated the ban on openly transgender military recruits, just two years after it had been lifted. Litigation regarding the ban is ongoing. At issue in the case banning transgender military recruits and several others is whether use of the word "sex" in Title VII of the Civil Rights Act of 1964, which prohibits employment discrimination based on "race, color, religion, sex, or national origin," includes SOGI information. Two major cases on this question were argued before the U.S. Supreme Court in October, but decisions won't be handed down until spring.

"Trans people in particular have unique privacy concerns around these issues," says Reisner, "because historically in order to gain access to hormones or surgery they would have to have a psych diagnosis in their chart, which could influence other kinds of care as well as insurance. If protections are taken away, having a formal diagnosis is very different from being able to indicate they're trans if they choose to. It may follow patients around."

The need to know

There's another aspect to privacy that's not in the forefront for patients or clinicians, and that is data collection, where challenges include defining and measuring sexual orientation and gender identity, obtaining high-quality cohorts from within relatively small populations, and again, overcoming the reluctance of some patients to come out to researchers.

The 2001 documentary *Southern Comfort* focuses on Robert Eads in the year before his death from ovarian cancer. According to the National LGBT Cancer Network,

1 in 72 people

who are born with ovaries will be diagnosed with this cancer during their lifetime. This includes transgender men who retain ovarian tissue. The National Cancer Institute estimates there are

22,000 new cases

of this cancer diagnosed annually in the United States.

Scientists who work in LGBTQ health centers like The Fenway Institute often have few problems recruiting self-selected volunteers. Reisner, for example, says he has not had any trouble finding research participants from the transgender community.

"There is a hunger for more knowledge," says the epidemiologist, who is trans himself. "The community wants to know the long-term impact of hormones, how our brains work, how stress increases cardio risk. Collecting data will increase our capacity to learn more about the population, specifically around biomarkers, to help us design interventions for improving health."

Studies using aggregated data from electronic health records and other sources, however, are lagging. Since 2016, the Bureau of Primary Health Care, part of the U.S. Health Resources and Services Administration, has required community-based HRSA Health Center Program grantees to collect and report SOGI data, and since 2018, all EHR systems certified under the federal Meaningful Use guidelines, part of the 2009 Health Information Technology for Economic and Clinical Health Act, are required to have the capacity to record that data.

But research has shown that most health care organizations have yet to implement such a system. One study by The Fenway Institute of 1,367 U.S. health centers found that SOGI data were missing for up to three-quarters of patients. This may be in part because patients are choosing not to share, but in many cases it's simply due to outdated systems.

Broadly speaking, research relies heavily upon labels.

For studies that don't look specifically at issues related to SOGI status, says I. Glenn Cohen, the James A. Attwood and Leslie Williams Professor of Law at Harvard Law School and an expert on bioethics, "many have inclusion/exclusion criteria that may relate to gender. One question is how to treat trans patients in particular. Is sex assigned at birth or the current sex the relevant criterion? We worry similarly about the underrepresentation of pregnant women in research studies, which happens in part because drug makers don't want to take risks, but in both patient categories the problem is it creates therapeutic orphans."

Broadly speaking, research relies heavily upon labels. "Asking how someone identifies in terms of sexual orientation or gender results in a preselected group with a well-defined, solid perspective on who they are and how they want to be viewed and excludes a lot of people who may not quite be there yet or haven't decided what certain words mean for them," says Webster. "Beyond that, there are so many different subpopulations. Queer might encompass Black lesbian cisgendered women and trans East Asian heterosexual men, but those two groups look very different. That's part of the challenge."

Of course, no matter the situation, it shouldn't be up to patients to figure out when they do or don't need to share their SOGI information. EHRs should routinely include not only options like queer, nonbinary, gender diverse, or "something else,"

say experts, but perhaps also a section for extant body parts.

"Let Robert Eads' life be a lesson," says Levasseur. "If you have a uterus or a prostate, don't be afraid to get it checked."

As with seemingly everything around this matter, though, it's not always so simple. "If you're a trans man who needs a Pap smear, but your health record says 'male,'" said Reisner during a panel presentation on LGBTQ health, "insurance won't cover it. One can call and advocate for one's patients, but it's an example of another system where there are barriers and structural stigma."

Reducing the stigma inevitably requires health care professionals and organizations to step up and educate themselves and their patients. "In increasing the recognition of the health needs of gender minorities," says Reisner, "the essential piece around provider training is integrating it into the curriculum. Physicians by and large have really good intentions, but they're also people, and if they have discomfort or lack knowledge, it may be more difficult for them to raise these issues without hesitation. We also have to let patients know they can talk to us without having anything being written in their medical record that they don't want there."

An open door

Many clinicians say they make an effort to show that their offices and waiting rooms are LGBTQ friendly, for example, by having copies of *Out* or *The Advocate* among their magazines, by displaying rainbow or unicorn

"Every time you see a new doctor or nurse, you wonder what the reaction will be and worry about the quality of your care. Will you be discriminated against when you're sick?"



Simple fixes like using the right pronouns and names can have a significant effect.

tchotchkes, and by hanging educational posters. Setting the right tone helps communicate to patients that the clinic is a place where they can talk about whatever's on their mind.

"I prepare myself before meeting people by doing several checks on my assumptions," says Webster, "and I try not to assume how they identify based on how they look or sound." He also asks his patients every six months or so if anything has changed. "It's a wonderful way for people to feel safe enough to bring more information into the conversation," he adds.

Even simple fixes like doctors using the right pronouns and names can have a significant effect.

"Only last year a study found that trans young people able to use their preferred names in multiple settings had fewer depressive symptoms, less suicidal ideation, and less destructive behavior," Webster points out. "So the use of chosen names really affirmed their gender identity and lowered mental health risks."

For the activist Green, who works closely with medical professionals on these issues, his own medical journey "has not all been a terrible experience, not at all." He says he has "tremendous respect and admiration" for providers who are working to educate themselves.

"The language is new, but the condition is not new," he says. "It has always been part of the human experience." **HM**

Elizabeth Gehrman is a Boston-based writer.

Insensitivity, or worse, discrimination, takes a significant toll on the health of LGBTQ individuals



On the Margins

BY JAKE MILLER

TWELVE YEARS. That's the average number of years of life prematurely taken from LGBTQ individuals who live in communities that harbor strong prejudices against members of sexual and gender minorities. The stress of living in an environment marked by stigma and structural discrimination can result in early deaths from suicide, from an increased risk of cardiovascular disease, and from a cascade of other life-shortening health conditions.

These findings were highlighted in a 2016 statement by Eliseo J. Pérez-Stable, director of the National Institute on Minority Health and Health Disparities, announcing that the National Institutes of Health was designating “sexual and gender minorities” as a disparities population. This designation served as a notification that the NIH recognized the health inequities affecting the LGBTQ community—and the need to address them.

The problems start early in life. Across the nation, lesbian, gay, bisexual, and transgender youth have an elevated risk of bullying, suicide, and substance use disorder and lack access to culturally sensitive and clinically specific LGBT health care, according to a 2017 review of the literature published in the *Cureus Journal of Medical Science*.

In adulthood, lesbians have a higher risk of obesity and breast cancer, and gay men face an increased risk of prostate, testicular, anal, and colon cancer.

“There’s no biological reason that minority people should be in worse health,” says Alex Keuroghlian, an HMS assistant professor of psychiatry, part-time, at Massachusetts General Hospital, and an active participant in efforts to build LGBTQ health equity in Boston, across the United States, and around the globe.

“It’s the result of various social determinants of health, of stigma, and of medical practice not being oriented toward including sexual and gender minority people. It’s a human-made problem,” he adds.

The daunting task of addressing the problem is magnified by the limited data available for researchers to analyze, use to assess clinical outcomes, or drive clinical improvements. Until the past few years, none of

the major national health surveys collected sexual orientation or gender identity data, and health systems haven’t had intake forms or electronic records that track sexual or gender minority patients.

This challenge was highlighted in the landmark 2011 report from the National Academy Press, *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a foundation for better understanding*: “Lesbian, gay, bisexual, and transgender individuals have unique health experiences and needs, but as a nation, we do not know exactly what these experiences and needs are.”

Now, with growing societal acceptance and legal rights for LGBTQ people, along with an increasing awareness of the health disparities that the community faces, physicians, researchers, medical educators, advocates, and members of the community itself are working together to make sure that LGBTQ people have equitable health care and the opportunity to live healthier lives.

A sense of the breadth of research occurring in the field can be found in a quick sampling of the more than three dozen papers, perspectives, and reviews authored or co-authored by Keuroghlian, who also directs the MGH Psychiatry Gender Identity Program and the education and training programs at The Fenway Institute in Boston. In just two years, he has had publications in *NEJM*, *JAMA*, and *Lancet* that address the damage caused by “conversion therapy,” ways to improve clinicians’ communication with LGBTQ patients, and the importance of capturing sexual orientation and gender identity data to improve health care. The work also gives a sense of how the knowledge base needs to be expanded and shared in order to provide more equitable, and more informed, health care to LGBTQ patients.

Teach, then teach some more

At HMS, Keuroghlian leads education efforts and curriculum development projects that help train health care providers and support staff at the School and at two of its affiliated hospitals: Mass General and McLean. He also is course director for the School’s fourth-year elective clerkship Care

for Patients with Diverse Sexual Orientations and Gender Identities.

“When I talk with people about equity for members of the LGBTQ community, they sometimes say ‘I respect everyone, I treat everyone the same,’” Keuroghlian says. “What we’re trying to help them understand is that all people are unique and need to be treated in a person-centered, tailored way. The key for physicians is getting to know your patients as people.”

More inclusive intake forms and electronic health record formats would be a step in that direction, according to a paper that Keuroghlian’s team co-authored in 2018 and published in the *Journal of the American Medical Informatics Association*. These improved forms would contain space in which physicians could enter data about a person’s sexual orientation and gender identity, their preferred pronouns, and the name they prefer to go by. That paper, a guideline of best practices for the collection of patients’ sexual and gender identity information, includes tips on finding ways to work around limitations in existing EHRs to collect this vital information.

The utility of gathering such data was further underscored in an August 2019 paper Keuroghlian’s team published in the *American Journal of Public Health*. In this paper, they reported the results of their analysis of sexual orientation and gender identity data collected by all U.S. health centers in 2016, the first year in which these centers were required to collect such information.

Physicians need to recognize the weight that repeated insults can have on a person’s health over a lifetime.

Their analysis showed that many patient records were still missing sexual orientation and gender identity data, but it also suggested that, when provided adequate training and technical assistance, health-center personnel were able to collect sexual orientation and gender identity data in a culturally sensitive way.

Framing the issue

The 2011 publication from the National Academies Press highlights the importance of using an integrative framework that takes into account the entirety of a person’s experiences and identity.

Physicians, according to the report, need to understand how multiple traumas over time accumulate in individuals who face discrimination and recognize the weight that these repeated insults can have on a person’s health over a lifetime.

For researchers, the report recommends combining the minority stress model with an intersectional framework to measure and interpret how sexual orientation and gender identity co-occurs with various social determinants of health and what effect those intersecting determinants have on the health of an LGBTQ individual.

Help with the math

Although efforts are underway to improve the collection of data to identify sexual and gender minority populations, researchers and clinicians who want to improve LGBTQ health equity struggle for adequate research funding and with the challenge of finding sufficient data in claims databases or EHRs to statistically power their studies.

“Given the limitations of the data that’s been available up until now, it’s astonishing that we know anything,” says Harry Reyes Nieva, a visiting postdoctoral research fellow in medicine at HMS and Brigham and Women’s Hospital and a doctoral student in biomedical informatics at Columbia University.

Reyes Nieva worked with Li Zhou, the principal investigator at MTERMS, a research group affiliated with the Division of General Internal Medicine and Primary Care at Brigham and Women’s, HMS, and Partners Information Systems, on a pilot study aimed at analyzing EHRs throughout the Partners system. When Partners officially rolled out a new EHR in 2015, the design included fields for recording sexual orientation and gender identity. Reyes Nieva and Zhou wanted to know if primary care doctors were collecting the information.



Although the results of the study are preliminary and unpublished, Reyes Nieva and Zhou say that their initial analysis provides a promising snapshot of physician participation and the feasibility of gathering sexual and gender minority demographic data throughout complex health care organizations like Partners.

The research duo also used machine learning tools to read free text typed into patient notes by providers to capture data about LGBTQ patients who were identified in case notes as LGBTQ but for whom no sexual or gender minority demographic data had been collected. Free text data is a rich source of information and usually is not available in larger databases, which collect only the information required for billing and claims.

“Using machine learning and other computational tools to mine data from electronic health records gives us powerful new tools that we can use to improve patient health,” says Zhou. “In minority populations it can be hard to find enough subjects to generate meaningful results. But by improving the data that we collect in EHRs and finding new ways to draw information from patient records, we may find insights that can help clinicians provide better care to individual patients.”

Reyes Nieva and Zhou are still analyzing the data from the pilot study for hints on how to improve LGBTQ health equity within the Partners system. An initial insight is that sexual and gender minorities have a comparatively higher rate of ambulatory

One outcome of this work is recognition of the need for provider training in administering psychotropic medication that is safe and effective alongside gender-affirming treatments.

care-sensitive conditions, that is, conditions for which treatment is possible and more cost-effective when dealt with in a primary care setting but which often are left untreated until the conditions require emergency department visits and hospitalizations.

Reyes Nieva says that this possible reluctance to seek timely medical care highlights the importance of building welcoming clinical environments and training staff to deliver culturally competent care that addresses the needs of LGBTQ individuals.

“There are small things you can do to signal to LGBTQ individuals that they are in a welcoming environment,” he says. “But once you’ve indicated it’s a welcoming environment, it actually needs to be welcoming and knowledgeable.”

To build this environment requires that LGBTQ training be integrated throughout the course of medical education; that LGBTQ physicians, faculty, and researchers are more visible; and that collecting data and generating research to inform how the medical profession can increase health equity and improve care becomes a priority, Reyes Nieva says.

Question, answers

Ana Progovac, an HMS instructor in psychiatry at Cambridge Health Alliance (CHA) who researches health systems, became interested in LGBTQ health disparities through a personal connection. After hearing about the challenges a transgender friend encountered when attempting to navigate the mental health system, Progo-

vac turned to peer-reviewed research for more insights into what her friend might be facing and how to help.

She was surprised by how little was known. There weren’t good estimates of how many transgender people were in health care systems, which makes it harder to plan how to prioritize appropriate services and coordinate care.

Working with the Health Equity Research Lab at CHA, Progovac used Medicare data to study mental health diagnoses and treatments for transgender individuals. Since these records don’t specify the gender identity of any patients, Progovac’s study design sought out diagnostic codes used to indicate gender dysphoria. The researchers used similar strategies to study care for transgender individuals in CHA’s patient records, which enabled the scientists to look for additional clues in the free text notes in those records.

Progovac published a study in 2019 in *LGBT Health* that examined trends in Medicare beneficiaries’ mental health care use from 2009 to 2014. Her paper reported that the proportion of patients receiving psychotropic drugs increased across the Medicare cohort, but it increased faster for gender minority patients than for other groups of older patients.

One outcome of this work, says Progovac, is recognition of the need for research and provider training in administering psychotropic medication that is safe and effective when prescribed alongside gender-affirming treatments such as hormone therapy, especially for older gender minority individuals who likely take several medications.

“All people are unique and need to be treated in a person-centered, tailored way. The key for physicians is getting to know your patients as people.”

Progovac's analysis of the CHA data has not been published, but preliminary findings showed that transgender individuals were being victimized by violence and attempting suicide at much higher rates than the rates recorded in the overall CHA patient population. Remarkably, when Progovac and her team shared their preliminary results with the members of the local transgender community, they thought that the estimates of suicidality and violence were significantly underestimated.

Hearing directly from members of the community was an important part of the research, Progovac says, because stories can be just as powerful as quantitative evidence.

"Different audiences need to hear different kinds of data," says Progovac. "We use big data sets like Medicare claims because they say something about what's going on in the whole country. I think those data sets are really important sources of data, and at the same time, I think when you're in a health system you really need to hear the stories from your own population."

The physicians and leaders of CHA have been eager to understand what transgender

Elders in the LGBTQ community who found ways to thrive might have insights that could help younger people face challenges throughout life.

patients experience when they come into the health system, says Progovac.

"When they hear these stories and see the data, people are very receptive, they want to know what they can do and what they should do next," she adds.

Inner resources

While it is crucial to identify the challenges that sexual and gender minority communities face, Progovac notes that it is also important to understand who's thriving and why.

"We need to make sure we also share the stories of how people find strength in the face of so much adversity," Progovac says.

As an example, she mentions "Resilience and Multiple Stigmatized Identities: Lessons from Transgender Persons' Reflections on Aging," a chapter by Susan McFadden and colleagues in the 2013 book *Positive Psychology*. The authors analyzed the qualitative responses of 122 transgender individuals aged 61 and older who participated in an online survey about aging. More than 70 percent stated they believe they are aging successfully, attributing some of their success to a combination of self-acceptance, personal agency, and nurturing, supportive relationships.


The researchers noted that elders in the LGBTQ community who found ways to thrive in spite of lifelong discrimination and stigma might have insights that could help younger people face challenges more successfully throughout life.

This hard-won resilience can also be a tool for improving clinical care, health

outcomes, and equity, Keuroghlian says. At The Fenway Institute, Keuroghlian leads the Evidence-Informed Interventions Coordinating Center for Technical Assistance, which provides national funding and support for programs aimed at improving HIV-related health disparities.

"We know lots of things that work," he adds.

In the face of jarring statistics about the harmful effects of living with discrimination, there is good news about the healing potential of supportive communities and shared lessons in resilience. Many of the programs supported by the coordinating center rely on the power of social networks within sexual and gender minority communities, Keuroghlian says, such as training people in peer motivational interviewing techniques to improve adherence for HIV treatment. These kinds of interventions, which use social strategies based on networking and solidarity, are an important part of the future of care delivery for sexual and gender minority communities, he says.

"The LGBTQ population has overcome enormous obstacles in a few short decades," Keuroghlian says. "If you can connect young people with that resilience, it can be profoundly empowering. In so many ways, resilience-based interventions are the future of health care for this population." 

Jake Miller is a science writer in the HMS Office of Communications and External Relations.

Ana Progovac



"We need to make sure we also share the stories of how people find strength in the face of so much adversity."

The persistent stress that sexual and gender minorities experience can lead to harmful mental health consequences

Pattern Constraints

BY JESSICA CERRETANI



“I wondered what it felt like ... to see the world open up to you in all its magnificence. What did it feel like to not have to think about your every move, to not be scrutinized for everything you did, to not have to lie every day?”

So wrote Garrard Conley in his 2016 memoir, *Boy Erased*, which recounts his time being subjected to “conversion therapy” as a gay teenager. The continual state of hypervigilance and anxiety, the fear of rejection, and the exposure to discrimination

that he describes is not unique to his experience nor is it seen only in those who have undergone tactics designed to change gender identity or sexual orientation. In fact, it’s a phenomenon that social scientists and others now term minority stress. Such chronically high levels of stress are common in stigmatized minority groups, including LGBTQ people, and are increasingly being linked to an array of harmful mental health consequences.

Indeed, recent surveys have shown that lesbian, gay, and bisexual adults are more than twice as likely to have a mental health condition as their heterosexual peers. Nearly 18 percent of LGBTQ youth have major depression, while 11 percent have post-traumatic stress disorder and 31 percent report



having considered suicide at some point in their life. Such statistics stand in stark contrast to rates of these same mental health concerns in the general U.S. population: slightly more than 8 percent for depression, nearly 4 percent for PTSD, and 4 percent for suicidal ideation. In addition, although research on subjective cognitive decline (SCD) is in its infancy, some early evidence of this self-reported increase in confusion or memory loss suggests that minority stress might be tied to a higher incidence of this condition among older LGBTQ adults.

A 2019 study out of the University of California, San Francisco, showed that for adults over the age of 45, more than 14 percent of sexual and gender minority participants reported the condition

compared with just 10 percent of the cisgender participants. Other research suggested that being a person of color or having depression further increases the risk of SCD in the LGBTQ population.

Minority stress can take many forms. It can arise because of continual exposure to various microaggressions such as being unrepresented in the media or being referred to by misgendered pronouns. Or it can come from threats like being harassed or bullied. Even the expectation of rejection and discrimination that results from past experiences can contribute to persistent stress.

“All of these chronic stressors get internalized and can manifest in mental health issues such as anxiety, depression, and suicidal ideation,” explains Michal McDowell,

“We’re seeing an increase in hate crimes, bullying, and homicides, particularly of transgender women of color. It’s clear that what happens at a policy level affects the health of this population.”

MD '17, an HMS clinical fellow in psychiatry at Massachusetts General Hospital, who has studied the risk of psychiatric conditions in patients who are transgender or nonbinary. "A lack of family or social support can compound minority stress and further reduce the ability to cope."

Not Mr. Rogers' neighborhood

Research reports leave little doubt that a hostile environment can worsen sexual and gender minority stress. Studies have identified higher rates of psychological distress and psychiatric disorders among LGBTQ adults who live in U.S. states that banned same-sex marriage or in states in which constitutional amendments to ban same-sex marriage were on election ballots. Likewise, state laws that permit the refusal of services to LGBTQ people, such as rejecting orders for wedding cakes or reservations for ceremonial venues, have had damaging psychological effects.

In one recent study, researchers looked at the potential effect of refusal-of-service laws among LGBTQ residents in Utah, North Carolina, and Michigan and found that they were associated with a 46 percent increase in LGBTQ adults experiencing mental distress when compared to peers in six states that were used as controls.

The problem isn't limited to adults. LGBTQ youths who reside in neighborhoods with a higher concentration of LGBTQ-targeted hate crimes or with fewer sexual orientation- and gender identity-

specific antibullying policies in place have a greater likelihood of suicidal ideation and suicide attempts than their peers who live in more supportive neighborhoods.

The problem also isn't limited to patients. For a 2018 study, Carl Streed, an assistant professor of medicine at Boston University School of Medicine and a primary care physician at Boston Medical Center, and his colleagues asked LGBTQ providers about their experiences in the workplace and found a slew of disturbing stories that ranged from fear of discrimination to actually being fired, fears and consequences that were associated with increased stress levels and unhealthy coping behaviors. An earlier study by researchers at San Francisco State University identified additional problems, such as harassment, derogatory comments, and denial of referrals from heterosexual colleagues.

Troubling times

Trauma has long-lasting consequences: Children and teenagers who experience LGBTQ-related victimization, both in person and online, have higher rates of depression, suicide attempts, substance use disorders, and psychological distress that extend well into young adulthood.

It's a crisis that doesn't promise to wane anytime soon. "The current administration hasn't hidden the fact that they are attacking the LGBTQ community," says Streed. "We're seeing an increase in hate crimes, bullying, and homicides, particularly of

Studies have identified higher rates of psychological distress and psychiatric disorders among LGBTQ adults who live in U.S. states that banned same-sex marriage.

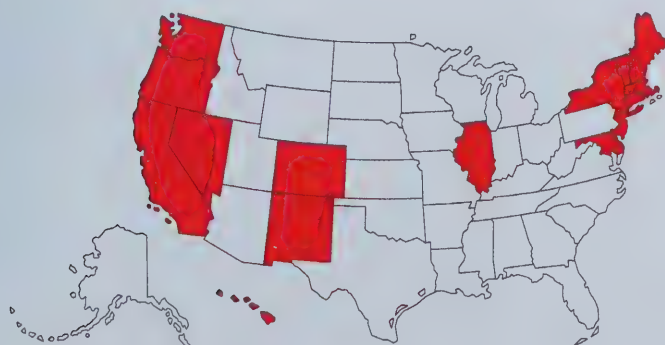
transgender women of color. It's clear that what happens at a policy level affects the health of this population."

Indeed, research indicates that members of the LGBTQ community have been experiencing a surge in discrimination and minority stress, and an increase of anxiety and depression, since the 2016 presidential election.

Affronts to identity

This uptick in stresses from society in general is compounded by the pseudoscientific practice of "conversion therapy" in minors, which remains legal in thirty-two states. No states have banned the use of this practice in adults. More accurately described as gender identity or sexual orientation conversion efforts, the "therapy" includes any attempt to change a person's identity from trans- to cisgender or their orientation from LGB to heterosexual. Such practices range from electroshock aversion techniques to behavioral techniques such as, in some cases, having boys spend less time with their mothers.

A pair of recent high-profile papers highlight the damage done by these gender-identity conversion efforts. In an August 2019 report in the *New England Journal of Medicine*, Streed and his colleagues called for an end to the practice, citing well-documented examples of the harm it causes, including higher rates of depression, suicidal thoughts, and suicide attempts and lower educational achievement, lower income, and lower work performance into



In November 2019, the American Medical Association adopted several new policies, including one supporting state and federal bans on so-called conversion therapy.

To date

18 U.S. states

as well as the District of Columbia have banned this "therapy" in people

younger than 18.

In addition, the AMA stated that it agrees with experts who say the lack of regulation of these practices ushers in "harm and trauma for many U.S. adults and children."

young adulthood. And a study published in a September 2019 issue of *JAMA Psychiatry* found that lifetime and childhood exposure to gender identity conversion efforts were associated with adverse mental health outcomes.

“The practice can lead to deep feelings of shame and internalized transphobia that in turn may lead to depression and even suicidal ideation,” says Jack Turban, an HMS clinical fellow in psychiatry at Mass General and McLean Hospital, who led the study, which involved The Fenway Institute in Boston.

Attempts to change gender identity may be especially damaging to young children. “We found that for those exposed to gender identity conversion efforts before age 10, the odds of attempting suicide were four times higher than for those who spoke with a professional about their gender identity but were not exposed to conversion efforts,” Turban adds.

Unwelcome ramifications

When it comes to LGBTQ health, clinicians have the opportunity—and obligation, argues Streed—to affect change at a policy level. But change must also come from within. The field of medicine has a history of caring for sexual and gender minorities that many consider checkered at best. The American Psychiatric Association, for example, took decades before deciding to excise homosexuality from the *Diagnostic and Statistical Manual of Mental Disorders*; today, some physicians remain reluctant to

The field of medicine has a history of caring for sexual and gender minorities that many consider checkered at best.

treat LGBTQ patients. In one recent survey by the Center for American Progress, a public policy research and advocacy organization based in Washington, DC, 8 percent of LGBTQ respondents and 29 percent of transgender respondents said that a doctor or other health care provider refused to see them because of their actual or perceived sexual orientation or gender identity.

Of course, most health care discrimination is far less overt and is often unwitting. Yet the effect of such discrimination on the mental health of a patient can be as troubling as that of intentional refusal to treat.

“Providers may use the wrong name or pronouns for trans patients, or there may be limited options for gender on intake forms and in electronic medical records,” says McDowell. Even an OB/GYN’s waiting room that’s decorated in stereotypical feminine colors and contains magazines that appeal only to some cisgender women can contribute to gender minority stress, since transgender males and patients with nonbinary bodies often require gynecologic services.

“All of this can make patients feel like they don’t belong,” she adds.

Intentional or not, fear of discrimination contributes to minority stress and can keep LGBTQ patients away from the doctor altogether. Surveys by the Center for American Progress have found that more than 6 percent of LGBTQ people said they avoided physicians’ offices within the past year due to concerns about discrimination. Moreover, the survey indicated that more than 18 percent of LGBTQ

patients who had already experienced discrimination avoided their doctor’s office in the past year, a percentage that was nearly seven times greater than that for peers who had not experienced such discrimination.

“The most pernicious effect of perceived discrimination is that people don’t want to see their physician for any reason,” says Streed. “If they don’t come in, we can’t provide them with even the most basic care.”

Along with leading to higher rates of mental health concerns, internalized minority stress has been linked to an increased risk of cardiovascular disease and other conditions, all of which remain untreated when patients avoid medical care.

According to Streed, physicians have a responsibility to provide care for LGBTQ patients that is both welcoming and affirming. It’s an approach that allows patients to feel safe and willing to share personal information with their doctors.

“As physicians, we need to be open with our patients,” he says. “Introduce yourself, tell patients your pronouns, and ask them what pronouns they use. Include questions about pronouns, gender, and orientation on your intake forms and electronic medical records.”

Data support this type of gender- and sexual orientation-affirming care. Studies suggest that support of sexual orientation and gender identity can act as a buffer against the negative effects of minority stress and is associated with higher self-esteem and lower rates of depression and suicidal ideation and suicide attempts.

“There are so many layers to identity that we’ll never know everything about our patients. The most important thing isn’t to be perfect, but to be humble, curious, and willing to learn.”



Even simple fixes like doctors using the right pronouns and names can have a significant effect.

“There’s new evidence that trans youths who are supported in their identities have mental health similar to cisgender controls,” says Turban. That’s a big difference from past studies, which found that unsupported trans youths have high rates of anxiety and depression.

The care-filled approach

Although it’s important to understand the distinct needs of LGBTQ patients, clinicians emphasize that there are more similarities in caring for this population than differences. Chief among them: the need for physicians to provide trauma-informed care to every

patient. A large proportion of this nation’s population has experienced some form of trauma. An estimated one in four children have experienced some form of abuse; the same ratio of women have experienced domestic violence. One in five women and one in seventy-one men have been raped.

For these reasons, providers should refrain from making assumptions about their patients. “We shouldn’t presume to know a patient’s gender, orientation, whether they’ve experienced trauma, or anything else,” says McDowell. “As providers, it’s our responsibility to take a complete medical

history and to ask all patients how they want to be walked through an exam.”

The same approach applies to mental health. “It’s really important to screen all patients for mental health concerns,” she adds. “Yes, LGBTQ people are at risk for depression and other conditions, but so are many people in other vulnerable populations, and we often don’t know who those patients are until we ask.”

Indeed, LGBTQ patients have the same wish for their medical care as anyone else would. “At the end of the day, they want to know that you’re on their team,” says Turban, who recently asked a focus group of gender-diverse youths what they wanted their physicians to understand. “Telling them that you accept them for who they are lets them know that you aren’t rejecting them, too.”

For many providers, the greatest challenge may be getting out of their own way. “As physicians, we tend to get uncomfortable when we aren’t an expert in something. We worry that we aren’t competent and that we’ll make a mistake,” says McDowell. “Providers can take continuing medical education courses to increase their comfort and competence.

“There are so many layers to identity—culture, gender, sexual orientation, race, ethnicity, or religion—that we’ll never know everything about our patients. The most important thing isn’t to be perfect, but to be humble, curious, and willing to learn.” ■

Jessica Cerretani is a Boston-based writer.



A 2018 study in the *Journal of Adolescent Health* reported that among a small cohort of transgender youth, those who could use the name they had chosen experienced a **29 percent** decrease in suicidal ideation and a **56 percent** decrease in suicidal behavior. Depressive symptoms, suicidal ideation, and suicidal behavior were lowest, the researchers reported, when the youths could use their chosen names in multiple contexts.

in 5

A conversation with Ann Hochschild, the Maude and Lillian Presley Professor of Microbiology and head of the Department of Microbiology in the Blavatnik Institute at HMS



Your undergraduate degree is in English literature. How did you end up in the world of microbes?

In my senior year at Radcliffe College, I had fulfilled the requirements for my major and was looking for a course about something different. Somebody mentioned the course on the origins of molecular biology taught by David Dressler, who was in the Biochemistry and Molecular Biology Department. I walked into that course naïve, not even knowing what DNA was. Dressler gave beautifully crafted lectures about the foundational experiments in the field and the scientists who carried out those experiments. He was able to convey the sense of suspense and excitement of discovery. I was mesmerized by it all.

Does your background in literature inform your work as a scientist?

I think maybe it informed my choice of PhD lab. I did my PhD with Mark Ptashne at Harvard. What appealed to me about his science was the narrative elegance of it. There are different styles of science, and as an individual scientist, you get more drawn to certain styles. For me, genetics has always been what I loved the most. I like its elegance, its indirection. Maybe I connect that with the kind of subtlety I like in literature.

What is the most pressing challenge for the field of microbiology?

The well-known challenges are antibiotic and antiviral resistance, and emerging viruses are also a huge problem. However, I think it would be a mistake to focus narrowly on those challenges. We have to

allow space for curiosity-driven research or we're going to find ourselves in a tunnel, perhaps missing something that could be transformative. To think we know what the most productive approaches are in any field of biomedicine is, I think, a mistake with potentially disastrous long-term consequences.

If you could pursue any other profession, what would it be?

It'd be something that relates to my interest in language. I'd call it a forensic philologist, a profession I don't think exists. I've always been interested in the way people use language and the idiosyncrasies in how people phrase things. I had a friend who got a grant review and wondered who was responsible for writing it. I figured it out—I looked at other writings by the various people in the study section and found one whose phrasing was unmistakably the same. I joked that I should start a cottage industry in which I'd figure out the identity of authors from writing samples.

As chair of microbiology, what's on your to-do list?

Junior faculty recruitment is something the whole department is incredibly excited about, as am I. We are recruiting in a new way for us, by inviting all our finalists for a symposium. We did this for the first time last year, and it ended up feeling like a festive occasion that reinforced a sense of community within the department.

—Ekaterina Pesheva

A patient's anatomical records from the 1800s give insight on intersexuality

Before Thomas M.'s story became part of the Warren Anatomical Museum, he was a patient at Massachusetts General Hospital seeking operative relief from a greatly swollen right testicle and its resulting pain. When surgeon Jonathan Mason Warren, MD 1832, examined the twenty-one-year-old patient in April 1859, he saw a "young working Irishman" with a "full, strong, and black" beard, whose "ordinary" larynx emitted a masculine voice. The recent testicular enlargement was accompanied by appetite loss, diminished "sexual desire," and painful swelling in both breasts. Warren saw Thomas as any other male surgery patient. "There was no suspicion of the true condition" until Thomas died.

As he prepared Thomas for surgery, Warren's concept of his patient's body changed. Beneath Thomas' penis was a "fissure" that revealed his urethra and "distinct" but "poorly developed labia." These observations were seemingly incidental to the surgery, and Warren removed the single testicle, which had been wholly "converted into encephaloid matter." Thomas succumbed to postoperative complications and infection, in addition to the cancer that was confirmed at autopsy. The autopsy also revealed the full uniqueness of Thomas' internal anatomy.

Harvard anatomist Richard Manning Hodges, MD 1850, conducted a "more minute dissection and investigation" of the patient's urogenital organs and described a "rudimentary prostate," a "well-formed uterus of normal size," and a "poorly-devel-

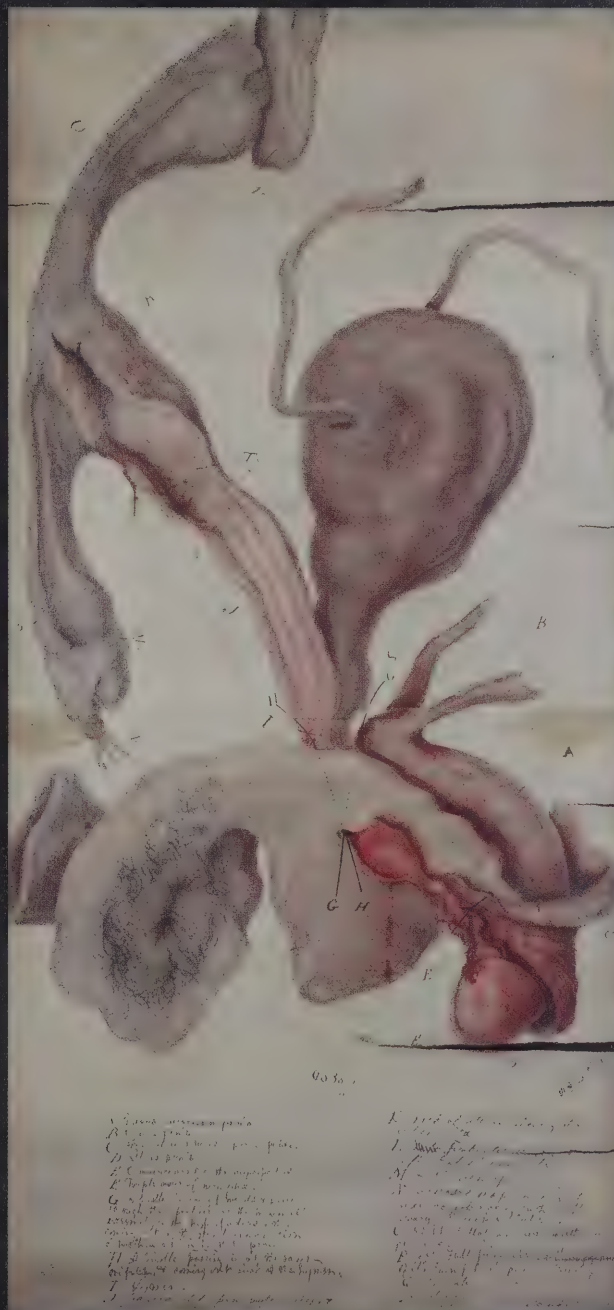
oped" left ovary. While Hodges believed that Thomas had a woman's internal anatomy, he and Warren could not account for the "genuine masculine formation of the body." Rather than providing anatomical certainty, Thomas' autopsy "very much disturbed" the physicians' conception of the "effect of sexual organs on the external characteristics." Spurred by this question, Warren preserved the tissue in the museum founded by his father.

What was Thomas' body to Thomas? It is difficult to know. He is largely silent in the known record; we know him only through his physicians. He was shy during Warren's exams and had never had sexual intercourse. The museum record states that Thomas had presented himself as a man when he entered the hospital, worked as a "seaman," and gave no indication that he questioned or was concerned about his place in society. It is likely that he would have never known the details of his internal anatomy. Yet, Thomas was described as "friendless," a term suggesting that he had no local support system.

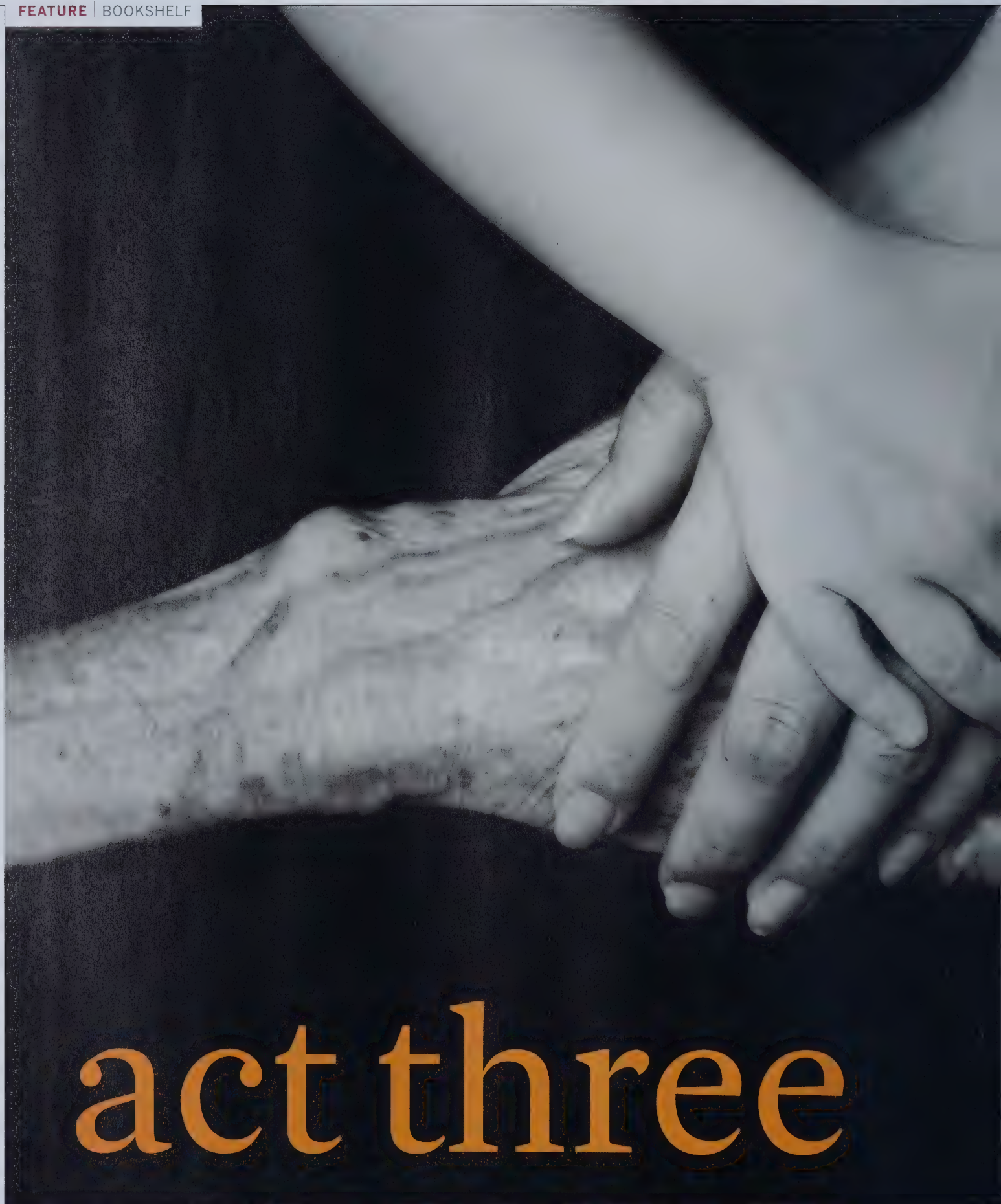
While the greater part of Thomas' life and experience is unknown, the telling of his story offers enduring lessons. His case is a testimony to human uniqueness and the long historical record of the body's resistance to the neat categories that science often seems to demand.

—Dominic Hall

Dominic Hall is curator of the Warren Anatomical Museum in the Center for the History of Medicine at the Francis A. Countway Library of Medicine.



Watercolor of the urogenital system of Thomas M. (1838-1859), a twenty-one-year-old sailor, painted by L. Manlius Sargent Jr., MD 1857, after removal by Shattuck Professor of Morbid Anatomy J. B. S. Jackson, MD 1829.



act three



From Louise Aronson's New York Times bestseller, *Elderhood: Redefining Aging, Transforming Medicine, Reimagining Life*, 2019. Excerpted with permission from the author and her publisher, Bloomsbury Publishing.

Too often, life's final act is viewed through lenses that are ground by society and fitted by medicine. A geriatrician argues that this needs to change.

OVER TWO THOUSAND YEARS AGO, Aristotle defined a whole as "that which has a beginning, a middle, and an end." He showed that in three-act dramas each part contains multiple scenes and serves a unique purpose. Most human lives follow a similar progression, from setup through complications to conclusion. Until recently in human history, people's individual dramas often ended early in the first act and certainly before the curtain fell on what we now consider Act II. The average life span was thirty to forty years, with childbirth, accidents, and infections routinely cutting lives short. These days, average longevity has doubled. With so much more time, each act contains more scenes, and most of us make it to Act III. Now, alongside childhood and adulthood, the vast majority of us can also expect a third act, or elderhood, that begins at sixty or seventy and lasts for decades. This third act is not a repeat of the first or second. More often, it is in life what it is in drama: the site of our story's climax, denouement, and resolution. ■ Those last two scare us. We desperately want our elderhood to be long, meaningful, and satisfying, yet most of us refuse to approach it with the same shameless ambition we reflexively accord childhood and adulthood. For the first years of my career, I thought I understood old age and how to create a comfortable, meaningful Act III for my patients. But once my parents entered their eighties and I turned fifty, I realized I had been mistaken. I found myself making all the same sorts of cracks and feeling all the same feelings about aging as everyone else.

DERIGHT/SIGNATURE/GETTY

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p until that point, I had believed that geriatrics, with its specialized tools and knowledge, had all the answers about

old age. But if geriatrics adequately addressed old age, wouldn't the rest of medicine and everyone else have adopted our philosophy and strategies? Clearly, geriatrics was to elderhood what we doctors call "necessary but not sufficient," and I began to wonder what I was missing ...

For most of us, Act III is long and varied. If we see it differently, our feelings about it might also change. And if we see and feel differently about old age, we can make different choices, ones that change our experience of elderhood for the better.

Sexy

Television serves as a rose-tinted mirror held up to our societal obsessions, conceits, and fantasies. Increasingly, it is weighing in on the topic of old age.

In the show *Grace and Frankie*, Jane Fonda (age seventy-nine in the third season) and Lily Tomlin (age seventy-seven) played scenes that often included jokes about one's hearing and the other's memory loss. Meanwhile, their now romantically partnered gay ex-husbands, Martin Sheen (age seventy-six) and Sam Waterston (also age seventy-six), after years of secrecy, at last let themselves come out to family and friends. Age liberated them from the conventions to which they submitted for decades, and the men finally claimed their true sexuality and identities.

In contrast to most casting, the male leads are younger than the females. Not by much, but Hollywood usually pairs men with women ten to thirty years their junior. Apparently, the rules of the game change in old age. This is Hollywood's traditional approach to heterosexuality across the life span: For the most part, teens fall for teens and young adults for young adults. In middle age, things change. Men fall for younger women, and women become mommies and bosses—roles commonly presented as mutually exclusive with sexuality and romance. In old age, the playing field evens up again, or maybe women gain a slight advantage. But it's not just women who are misrepresented. The association of manhood with virility is so strong that older men are put in a lose-lose situation, either portrayed as impotent in all senses of that word or described in language that suggests their sexuality is surprising, inappropriate, unbecoming, or repulsive. Jokes along the lines of "Grampa got game!" (said of Robert De Niro in the movie *The Intern*) commend thoughts and behaviors considered normal from age twelve through adulthood.

Despite its charms, *Grace and Frankie* sends mixed messages. The leads are all attractive, even if Fonda and Tomlin would not have been considered aesthetic peers in decades past. (Old is old is old ...) None of the characters have completely gray or white hair, and, given the commonness of hair loss in male old age, it's hard to believe that the selection of two still follicularly endowed male actors isn't meant to

Old age will only be respected if it fights for itself, maintains its rights ... and asserts control over its own to its last breath.

—Cicero

signal ongoing vitality. We are not the first generation to link sexuality with youth or to downgrade women years or decades before men.

A widowed friend in her seventies is often assumed to be much younger than she is. She has a great brain, a good sense of humor, flawless grooming, and a full life, but men don't look at her much anymore, and she hates that. When I last saw her, she regaled me with stories about her recent adventures in online dating. Her conclusion: "I don't want to be a nurse or mommy and only men looking for one of those look at me." The ones who might have interested her were looking downward chronologically, not across.

Other straight women find relief in the sexual invisibility of their old age. This has less to do with a loss of interest in sex than with the pleasure of shedding the need they once felt to groom, preen, perform, and perpetually prove their worth by asserting their attractiveness to the male gaze. Those women still make an effort to look good but are happy to worry less about attractiveness, to have more time for other pursuits, to feel safer out in the world, and to celebrate a more honest and accurate alignment of their inner and outer selves.

Some have argued that because of gay male culture's focus on a young, buff, and beautiful version of sexual attractiveness, aging may be particularly difficult for gay men, especially those who are estranged from family or lost many peers in the early years of AIDS. Some of this is supposition, as little research has been done on sexual attractiveness and activity of LGBTQ elders. A search of the literature on the topic yielded primarily articles about sexual identity and health-related sexual challenges in old age. We know even less about lesbian, trans, or gender-fluid old people, though we do know that as groups they are more marginalized and have poorer health, two situations not generally correlated with sexual appeal.

Regardless of sexual identity, men are often said to have more options, and while that appears to be true, their romantic old age has its own disappointments. Men report surprise when their once effective charms aren't even noticed or, worse, are considered cute or absurd. All they want is what they've always wanted. The sports-writer and essayist Roger Angell, in his nineties, put it this way:

More venery. More love; more closeness; more sex and romance. Bring it back, no matter what, no matter how old we are. This fervent cry of ours has been certified by Simone de Beauvoir and Alice Munro and Laurence Olivier and any number of remarried or recoupled ancient classmates of ours. Laurence Olivier? I'm thinking of what he says somewhere in an interview: "Inside, we're all seventeen, with red lips." ...

Sexiness also matters in the world of health care, where the unofficial label for higher-caste diseases, patients, problems, and solutions is sexy. Heart disease is sexy. Cancer is sexy. All things procedural are sexy. Aging is not sexy. Since hearts and tumors are neither attractive nor desirable, the problem isn't one of aesthetics. It's one of value, both medical and social.

Lots of "not sexy" ailments can accompany old age. People with incontinence, falls, arthritis, constipation, insomnia, and vision

and hearing loss often give up jobs and treasured activities. They lose confidence, comfort, and eventually friends. Some fall prey to profiteers promoting unproven therapies. This downward spiral doesn't affect just the afflicted individual; it affects us all, socially and economically, directly and indirectly. Fear and shame lead to inactivity and shrunken social circles, two of the strongest predictors of poor health and the need for expensive services.

Imagine being incontinent. Your underpants are wet, cold, and itchy against your skin. You worry that you smell. You live in constant fear of accidents, the wetness showing through your clothes. You avoid events that last too long or without easy bathroom access. At some point, there's an episode that leaves you so embarrassed and ashamed that you stop going out. Thirteen million Americans are incontinent, and half of noninstitutionalized people over age sixty-five report urinary leakage. Incontinence is among the top medical reasons preventing people from going out and leading to institutionalization—outcomes that adversely affect health and quality of life. Traditionally, doctors and nurses haven't asked about incontinence the way they ask about other common symptoms, and patients haven't brought it up. Many assume little can be done. In fact, often little is done because, like the general public, doctors and nurses receive inadequate education about how to manage it.

All geriatric problems have multiple effective treatments. But only some offer cures with the clean-cut outcome of cataract surgery, one of the sexier treatment options for an age-related disease. Yet the "less sexy" treatments often make life worth living. Imagine what might be possible if these conditions and management strategies were given the same respect as high blood pressure or athletic injuries and their treatments. Just as caste systems keep lower castes in a relentless cycle of poverty and drudgery, so does medicine's sexiness hierarchy deprive millions of Americans of healthier, fully engaged lives. ...

Over coffee, a young man who works at a large, familiar tech company tells me they are moving into the "aging space." There's money there, he says, and opportunity—in other words, it's becoming sexy, at least to the higher-ups with their eyes on changing demographics and the corporate bottom line. Farther down the company food chain, however, the staff isn't feeling the passion. Being assigned to the aging project is considered the worst assignment: Sad. Lame. A drag. A bummer. A punishment.

My acquaintance confides that he only agreed to lead this project to get his foot in the door, but as he's spoken to actual old people (something he'd never previously done), he realized two things. First, spouse-partner-friend caregivers are shocked that he's using the words older adult to refer to them, not just the person they care for, though to his eyes they are "no question, old." Second, he can't get even his middle-aged colleagues to approach the aging project in the same way they approach all other projects: objectively. Instead, they tell him about their father or grandmother, going straight to stories of disaster and decline. In company brainstorming groups where discussions are usually based on facts, they ignore

We're all old people in training.

—Joanne Lynn, MD

the research reports he has provided and instead exchange loss and debility anecdotes. He can't get them to see that the experiences they are emphasizing may not be representative and that old age can be approached with the same open mind and intellectual rigor as every other topic.

Geriatrics frequently elicits the same reaction. One of the most well-known and influential physicians in America has described my specialty as "difficult and unappealingly limited." I'm biased, obviously, but how can a field devoted to caring for all medical conditions of all people in one of life's three decades-long age groups be described as limited? It's similarly worth considering why we hear a lot about surgical difficulty, but never that it lacks glamour. To me, all that cutting and rearranging is repetitive and dull—I cannot imagine spending my days that way—but I'm able to appreciate its value to patients and the world.

In medicine, some specialties are tops, while others are bottoms. But here's the rub: when we treat entire categories of people as less interesting and worthy, we devalue part of their humanity and forfeit some of our own.

Bodies

You don't have to be a doctor to recognize that the body changes with age, and you don't have to be officially old to know from personal experience that many of those changes are unwelcome. The physical and physiological changes that accrue to "old" begin subtly and early, in a person's thirties or forties, and at some variable point in our sixth, seventh, or eighth decade, we pass the physical, social, and legal thresholds of old age. The negative parts of this transformation—the losses—initially require adaptation, then limitation, and sometimes, finally, renunciation or the need for work-arounds. None of us want a cane, much less a walker, or help with finances or driving or grocery shopping. And uniformly, we don't want to end up hopeless, helpless, and institutionalized—most people's image of advanced old age and, often enough, at some late point, its reality. If you also consider that—unlike the terrible twos, a traumatic adolescence, a squandered young adulthood, or a midlife crisis—what follows being old is death, it becomes clear how old age achieved its current reputation.

Healthy, able-bodied people often say they wouldn't want to live with grave disability. Meanwhile, a majority of people who become

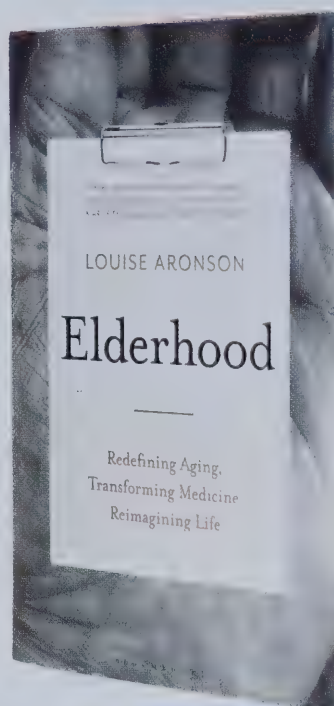


disabled—after an adjustment period—report good and, not infrequently, very good quality of life. Yet, when I suggest to friends in their seventies and eighties that a good part of the suffering in old age is manufactured by our policies and attitudes, they work hard to fill their expressions with nothing but curiosity and interest. In their eyes, I see suspicion, disbelief, and several unspoken retorts: She's too young to understand. Facts are facts, biology is biology, and we are all destined for more or less the same downward slide to oblivion.

Their reaction depends a bit on what kind of day or week or month they're having. Being sick or in pain or the recent death of a friend colors everything, and each of those things is increasingly common with age. People who are relatively healthy but have the pain or limitations of chronic diseases wonder what will happen next, and when. They worry about suffering and dying, about the loss of the people they love best, about being alone and about being gone. Those who are frail and sick or heading that way worry they won't die as soon as they'd like to. Others, with lists of ailments and medications long enough to unfurl like scrolls, fight to stay alive, even as ever greater proportions of their days are devoted to the basics of body tending: hygiene, and food, and medications.

People with highly restricted lives—the sorts of people in our housecalls practice, for example—lament less their lives' small stages than the accompanying isolation. The official term for the space we move through in the world, whether large or small, is life-space. Mine extends to continents; theirs is often limited to their home, a single room, or a bed. They would like to get out, to again be the sort of person who could or would go more places. But that's not the source of their greatest hardship. What they miss most, what they are starved for, is engagement, touch, conversation, and connection, those basics of being human that come in just above our needs for food, shelter, and safety on Maslow's hierarchy. Much has been made of what missing touch and connection did to Romanian orphans. The impact of isolation in old age, of never or rarely being touched or talked to or loved, is less formative but no less profound. Social isolation and loneliness worsen physical and mental health, leading to nursing home placement and premature death. In the UK, a young man spent a week alone in an apartment as part of the Loneliness Project, and although he started out okay, over the week he became increasingly frustrated, bored, despondent. He focused on small daily tasks, little things gnawed at him, he tried to turn off his brain, and he watched TV or went to bed for lack of other options.

On FaceTime, my mother, in the lobby at her gym, holds her phone midway between her mouth and ear. In public, she doesn't want it too loud, but in each of the last two years, she has consulted an audiologist, wondering whether the time for a hearing aid has arrived; on her most recent visit, they agreed she was getting close. I'm on



**For age is
opportunity
no less /
Than youth
itself, though
in another
dress**

—Henry
Wadsworth
Longfellow

my computer. Her cheek, one eye, and parts of her nose and lips fill its large screen. This close, the softness of her skin seems visible. It has a laxity, a slight droop, creases, and texture. It is subtly colorful, a canvas of tans, pinks, and off-whites. She has blemishes, too, darker patches hinted at beneath the makeup she has put on to hide them. At the corner of her lips, I see an irregularity, and the doctor in me considers diagnoses to explain it. I smile at the sight of the small pale pouch under her eye; she hates it, just as her father in his old age hated his. For fifteen minutes, I talk to my mother while watching this video of the side of her face. It's no less captivating than the several art films I have recently seen, and no less beautiful.

Do I imagine I see the softness of her cheek because I have kissed that cheek and know the feel of it on my skin? Is it because her cheek is so familiar—likely the first skin I kissed over a half century ago—and because I love my mother? Or is it because I know in some essential way that if something looks as her cheek does, it's soft to the touch, warm, yields on impact with a gentleness that is inviting and comforting. A younger cheek, taut and smooth, is more like a trampoline; a touch doesn't sink in so much as bounce off. Later than night, climbing into bed, I realize that, for me, faces are like bedsheets in winter. My favorites are our oldest, soft and welcoming from years of use. When we use the newer ones, my heart sinks. They are nicer to look at but crisp and cold on my skin. ...

Coda

A good life, like a good story, requires a beginning, a progression, and an ending. Without those defining elements, it feels partial, even tragic; it lacks shape, purpose, and meaning. The end may be hard and sad, but even when we don't want a story to end, the best ones leave us with a sense of completion and satisfaction.

The left-brain fixers among us offer only instruments. Sometimes these are lifesaving or life enhancing; other times, their unintended consequences overshadow any benefits. Without due diligence about who chooses the questions and tools, who benefits, and who might be gravely harmed, what appears to be progress can be anything but. Science and technology can only ask and answer certain sorts of questions. Those instruments, although now considered synonymous with progress in both medicine and life generally, will become socially and morally responsible only when they are paired at the outset with equal consideration of their origins, intent, and impact on people of all ages and backgrounds.

Events are judged not on their entirety but on their moments of peak intensity and on their endings. And what is life but a long, messy, awful, wonderful event? Elderhood is life's third and final act; what it looks like is up to us. ■■

Louise Aronson, MD '92, is a geriatrician, educator, and professor of medicine at the University of California, San Francisco.



Dynamic (Duo)

SOME PEOPLE SET LIMITS ON LIFE. Others, like P. Oneeka Williams, do not. In fact, her motto, "Not Even the Sky Is the Limit!" is one she lives and expresses vibrantly through Dr. Dee Dee Dynamo, the character in the children's books she writes.

Williams found a launching pad for her boundless energy and optimism for medicine in the New Pathway curriculum at HMS. "It created a context about what we were doing and why and provided us with an understanding that the practice of medicine was about treating the whole patient," says Williams, a urologic surgeon.

Williams says she was fortunate to have mentors such as Alvin Poussaint at HMS, Jonathan Mann at what was then the Harvard School of Public Health, and John Libertino at the Lahey Clinic. "They set high standards and supported you. You knew they believed there was nothing you couldn't do."

Williams internalized that lesson and is promoting it to children, especially girls of color, through her series of books featuring Dr. Dee Dee Dynamo, a super surgeon with magic hands. She cites a study from Columbia University, which found that "by the time girls are six, they don't believe they can pursue careers that require brilliance." Her mission is to change that narrative.

Born in Guyana to a science teacher and a journalist, Williams comes by her interest in science and storytelling naturally. "Much of what I do is at the intersection of storytelling, healing, and teaching. Even in a patient interaction, the first thing I do is listen to their story and then weave that story to help me understand the medical history, what the diagnosis is, and what am I going to do about it."

Williams tries to embody what she calls habits of positivity—a way of thinking that says a limit can always be converted into an opportunity. She has imbued Dr. Dee Dee Dynamo with that same spirit. "Literally her world is my world. Her journey is my journey. Her belief of positivity is really my positivity."

Glancing at the arc of the career she began 25 years ago, Williams is surprised by how little has changed in surgery: "I feel like change has not occurred as quickly as I would have expected in terms of women's roles, women in surgery, the mentalities of male dominance, and some of the misogyny that I encounter daily." This reality is a strong motivating factor for her work outside medicine.

"You really can't undo things that are deeply embedded," she explains, "until you start at the beginning and change the way we educate and expose all of our kids, boys and girls."

—Susan Karcz

Persis Oneeka Williams, MD '93, clinical assistant professor of urology, Tufts University School of Medicine | urologic surgeon, St. Elizabeth's Medical Center, Boston | author | president and founder of Dr. Dee Dee Dynamo

Student Life

Edgar Garcia Saiz

MEDICINE'S SOCIAL SIDE might be invisible to some, an abstraction to others. For Edgar Garcia Saiz, a second-year MD student, a deep caring for the social aspects of medicine was part of his way of thinking from an early age: His mother had a heart attack when he was in middle school. Underinsured, she hesitated over getting the care she needed at a crucial moment, opening Garcia Saiz's eyes to an old reality and a new opportunity.

"I saw a career in medicine as a way to advocate for patients with difficulties in accessing health care," he says. As a Harvard undergraduate, Garcia Saiz minored in sociology, work that led to his involvement in LGBTQ community building, such as staffing a late-night mental health hotline, working with the LGBTQ office of student life, and reviving Harvard's chapter of SHADE, a group for LGBTQ students of color because, he says, these students were "falling through the cracks in our programming and had difficulty finding an LGBTQ community that represented their diverse backgrounds."

Garcia Saiz says the support he receives at HMS is profound and a bit surprising. His faculty mentors are leading lights in the LGBTQ world, and they have helped him find his path. When Garcia Saiz looks into his future, he sees himself starting an LGBTQ health clinic that integrates care for patients.

"There's not really one single issue that affects LGBTQ people—it's very cross-specialty: primary care, infectious disease, psychiatry, and even pulmonology, which means all providers have to be adequately trained to provide culturally competent care," he says.

"When I worked at a mental health hotline," he adds, "many people I talked to said they often stopped seeking care because of negative experiences they had with providers who judged them on the basis on their identity or background."

Pediatric mental health has become the focus of Garcia Saiz's research project at Boston Children's Hospital. There, he works with Sabra Katz-Wise, an HMS assistant professor in pediatrics at Boston Children's, on how family functioning and support influence trans youth health outcomes, such as depression, suicidality, and anxiety.

Garcia Saiz's project investigates how familial support for a child's transgender identity influences sexual health outcomes—specifically, how family functioning influences riskier sexual behaviors later in life and whether there can be an effective early intervention.

What he hopes to discover is whether and how families supporting and respecting a child's gender identity can lead to better health outcomes with respect to riskier sexual behaviors.

—Susan Karcz





JOHN SOARES (OPPOSITE AND ABOVE)



Aliya Feroe

WHEN ALIYA FEROE was in preschool in Minnesota, her teacher called her parents to discuss Aliya's unusual approach to self-portraiture: While the other kids were drawing stick figures, Aliya drew figures that featured a spleen, heart, and stomach.

Feroe, now a third-year MD student, came by this anatomical knowledge honestly, as she frequently accompanied her father, a nurse, to work and played with the anatomical models in his office. This is her earliest memory of being captivated by the human body. Later, this interest would find expression in a love of sports and as an athlete.

During her undergraduate studies at Bowdoin College, she became "fascinated by the health of whole populations, with how societal structures interact to give some people an advantage and others a disadvantage. I was no longer able to separate my fascination with the human body from the ever-apparent social determinants of health."

Feroe entered HMS thinking she would go into OB/GYN, having done some work in child and maternal health at the Centers for Disease Control and Prevention and at Boston Children's Hospital. That thinking was turned on its head after research projects at the Harvard-affiliated hospitals and a third-year rotation in surgery. Feroe fell hard for the operating room, in particular pediatric orthopedic surgery and sports medicine.

Although she is grounded in the medical side of health, Feroe continues to develop her interests in the societal side of the discipline. She is applying to master of public health programs and hopes to use both medicine and public health to effect social change.

One way she is already working on social change, along with other medical students, has been with the Sexual and Gender Minorities Health Equity Initiative, a grant-supported curriculum reform initiative that she helped launch at HMS last year. This initiative focuses on educating

students as well as faculty on how to effectively care for patients who identify as part of a sexual or gender minority group.

Citing her involvement in this group as an example of the kind of support she has received at HMS, Feroe says that "from the beginning, I've been really impressed by the interest among administrators about getting change to happen." She found this a bit surprising because "where I grew up, my impression of Harvard was a place with white marble walls where I wouldn't belong." This turned out not to be the case, and "right off the bat I was surprised by how open-minded people are, and willing to help and eager to learn."

Feroe is not yet sure where she will land after her formal education is complete, but she is feeling pulled back to her roots in the Midwest and Scandinavia, her family's region of origin. Wherever she finds herself, she will blend medicine with policy—and add a dimension to her self-portrait.

—Susan Karcz

Jordan Said

ACCORDING TO JORDAN SAID he's always been comfortable being out at HMS. "I've never felt like I had to hide that part of myself."

HMS also has enabled Said, a third-year MD student, to incorporate his identity and interests into his professional goals. In his first two years at HMS, Said was a member of a working group that identified ways to improve components of the School's curriculum related to LGBTQ health. The group's findings have shaped the Sexual and Gender Minorities Health Equity Initiative (SGM), which aims to integrate culturally competent care for LGBTQ patients into the School's core MD curriculum.

Said completed his clinical clerkship at Cambridge Health Alliance, where he was involved in the Transgender Health Committee, which is developing and promoting resources on transgender care for all the hospital's health care providers. "Everyone has patients who are LGBTQ. Everyone should know how to take care of a trans patient, for example," he says.

With the support of faculty leadership and the HMS student-led Racial Justice Coalition, Said and two classmates designed and presented a workshop on recognizing and competently addressing microaggressions arising out of racism, sexism, or homophobia that may be encountered in the clinical setting. They went on to present their material at poster sessions at local and national conferences, where their material garnered special recognition.

"I think it grabs people for two reasons," says Said. "One is because it hasn't been addressed yet. The other is because it's so commonplace."

Despite both of his parents being physicians, Said came to medicine on his own. He loved biochemistry and cell biology and thought he would be a bench scientist, pursuing a bachelor's degree in molecular and cell biology at the University of California, Berkeley. While there, he volunteered as a lay medic at the Gay Men's Health Collective at the Berkeley Free Clinic, an experience that helped him realize he could fulfill his interest in working for social justice by becoming a physician.

Said hopes to participate in the HMS clinical elective dedicated to LGBTQ health at Boston Children's Hospital and is considering specializing in OB/GYN or dermatology. For the remainder of his student years, he plans to remain involved in the School's SGM initiative, an effort he thinks will help HMS grow as a leader in health education and delivery for the LGBTQ community.

—Bobbie Collins





Brotherhood

The warmth from a friendship kindled decades ago glows again
by Stewart Gilbert



EXPLORATION WAS MY MEDICAL SCHOOL

safety valve. I had come to HMS after earning a master of science degree and after serving in the Peace Corps and a stint in the U.S. Army. While my graduate work took place in Pennsylvania, my time in the Peace Corps took me to Addis Ababa, Ethiopia, where I taught general science to ninth graders and general chemistry to tenth-grade students at the Tafari Makonnen School. My time in the Army found me once again in the United States, stationed in Natick, Massachusetts, where I worked in a research lab by day and, at night, as an orderly off base at the Leonard Morse Hospital.

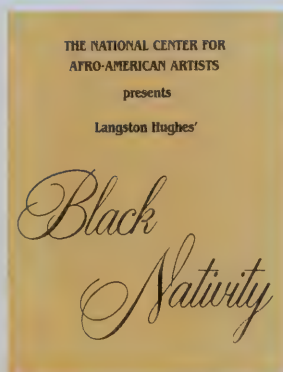
Those experiences fueled my interest in exploring extracurricular opportunities outside of HMS. Venturing into the diverse cultures that surrounded the School provided me with opportunities to decompress and balance the demands of academic life. As often as possible I attended concerts by the Boston Pops, Red Sox and Bruins games, and performances at the Elma Lewis School of Fine Arts, notably its annual production of Langston Hughes' *Black Nativity*. I also developed an affinity for the Roxbury community and for Boston City Hospital, where I did most of my rotations. I was privileged to be a guest in the homes of several of the patients I treated.

Being a church kid, I continued worshipping while in Boston. Under "watch care," I was given a temporary spiritual home at the Twelfth Baptist Church in Roxbury, and I also enjoyed frequenting the spirited services of a nearby Church of God in Christ. My favorite getaway destination was the quaint fishing village of Gloucester, Massachusetts, on Cape Ann.

My GI benefits together with my salary from my night shift job—typing the metal ID plates for patients newly admitted to the wards at the former Peter Bent Brigham Hospital—provided some discretionary funds. From this income, I eked out about \$2,000 for the purchase of a new 1972 beige Ford Pinto.

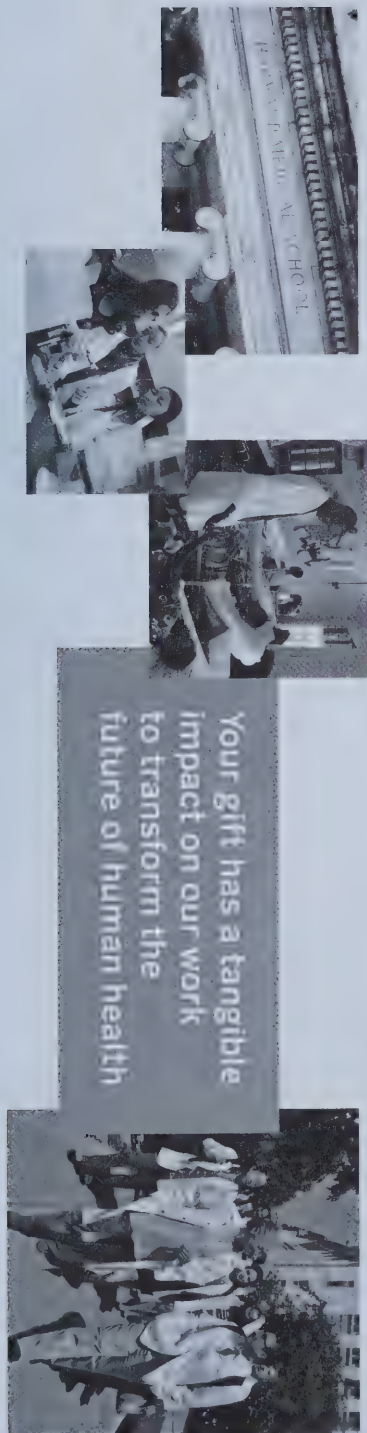
Game days

Another of my off-campus experiences involved volunteering for Boston's Big Brother program. I was matched with Bernard, an 8-year-old boy who lived in Roxbury. Bernard's mother had asked to have her youngest son become part of the program; as a single mother of five, she had concerns for him.



A program cover, circa 1980s (left), and a still from a 1974 performance of *Black Nativity* (above) are among the materials produced during the nearly five decades that the play has been staged in Boston.

Bernard and I would get together on my available weekends, usually once or twice a month. We saw the Sox, the Bruins, and the Celtics play, and we visited arcades, hit the zoo, took road trips, and celebrated milestones, including birthdays, which I am especially fond of celebrating. We had great, fun times together that, in the process, allowed me to relive my boyhood.



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DO NOT WRITE BELOW THIS LINE



The Pinto, portrayed in this vintage advertisement from the year the car debuted in North America, ferried the author and his Little Brother on numerous trips around the Boston area.

After two years in the program I attempted to prepare Bernard for my departure through affirmation and encouragement. Because Bernard's father was in his life, I had never tried to take his dad's place. But Bernard and I were close, so I wanted him to know about my upcoming graduation and the coming change and to understand it.

I was matched to an internship at what was then the Harbor General Hospital in Torrance, near Los Angeles. I got together with Bernard and said my good-byes, packed the Pinto, and prepared for the 3,000-mile cross-country trip to my new home. Time constraints and the need to visit my home in Tulsa, Oklahoma, along the way meant that I left HMS before some of the graduation exercises—something I regret to this day.

My new assignment at Harbor General brought its own challenges, ones that were even more daunting and time-consuming than those I'd faced in medical school. Soon, I lost contact with Bernard.

A shared moment of life

California was good for and to me. I successfully completed an internship and residency in internal medicine and followed that with a forty-year practice in communities similar to Boston City Hospital and Roxbury.

My first job as a primary care physician was with the Watts Health Foundation in Watts, California. I later helped found a small internal medicine group partnership in Inglewood. Along the way I met my wife. She was a nurse in the ER that I worked in during my residency rotation. Our courtship was from a classic soap opera set in a hospital ER. Over the years, we became the parents of two beautiful daughters.

On the occasion of my eldest daughter's forty-first birthday, which we celebrated at a local Los Angeles restaurant, I asked my daughters if they had any unanswered family history questions. My question sparked a revealing and spirited conversation that prompted me to decide to make each of them a pictorial genealogy tree.

While sorting through old pictures, a 3½" x 4½" Kodak color print fell to the floor. It was a picture of a young boy dressed in a heavy, plaid winter coat and leather cap. Eyes shut by a humongous smile that showed all his teeth, he was holding a large, round, blue and white cake on which was written "Happy Birthday Bernard." On the back of the photo, his mother had written "Bernard Feb. 16, '74. Age 10. His Big Brother gave him the beautiful cake."

Although I had been back to Boston on a few occasions after graduation, I had been unable to locate Bernard. Most of the visits were in the pre-internet age, so my searches relied on the white pages in the local telephone directory. I did not find his name. As recently as two years ago, when I accompanied my firstborn on a visit to Wellesley College, her alma mater, I was still unable to connect the dots.

As online searching became more common, I tried to locate Bernard that way. I found most often that search sites would tempt me with a bit of information, then lead me on a course that ultimately required my personal information and credit card data. Whenever I reached that point, I opted out.

A verse in Ecclesiastes comes to mind: Cast thy bread upon the waters, for thou shalt find it after many days.

But after finding Bernard's picture, I decided to try another online search. I entered his name, state of residence, and the newly found date of birth. Immediately, a match popped up. It offered an address and a phone number. Being somewhat anxious about how to proceed, I decided to send a text.

"Dear Mr. T., my name is Doctor Stewart Gilbert, and I am trying to locate a Bernard T., who would be about 54 years old, who I worked with in Boston in 1973 in the Big Brother program. Would you be him by chance?"

I checked my phone frequently, hoping for a reply but also realizing that for many complex reasons there are people who prefer not to revisit the past.

A day passed without a response. Then, on the second day after my text, I received a reply.

"Dr. Gilbert I am that skinny little boy you're looking for. WOW. I still remember the day my life changed."

Wiping away tears, I sent him my contact information and a copy of the picture of him holding that white and blue birthday cake.

We have since talked by phone and are planning a meeting soon. He recalls some of our adventures in detail and remains appreciative of our time together. One of the things he told me was that he had a difficult time explaining to people why his first car, a Ford Pinto, had "STU" on its license plate.


Despite how pleasant our conversations were, I sensed he had a lingering question around my Boston departure forty-four years ago. I was right. In subsequent conversations I learned that, despite my attempts to prepare the young Bernard for my departure from Boston, he felt I had deserted him. He also told me that over the many years since I had left the city, he had prayed for me.

After I left Boston, Bernard joined the Boy Scouts, played sports, including hockey, and later, enlisted in the U.S. Army. He is now a retired firefighter and a doting father and grandfather. I learned he had been aware of my location but had held off contacting me, as he didn't want to intrude upon my new life.

Outcomes

In the sunset of your years, you take inventory and reflect upon legacy. You realize that relationships are of paramount importance. The fact that Bernard and I reconnected after more than four decades was truly a gift from God for both of us.

I am a man of science, but I also am a man of faith. My career in medicine may have set the stage for our meeting, but the relationship that developed was one in which I think the fellowship of faith played a role. As I reflect on it, a verse in Ecclesiastes comes to mind: Cast thy bread upon the waters, for thou shalt find it after many days.

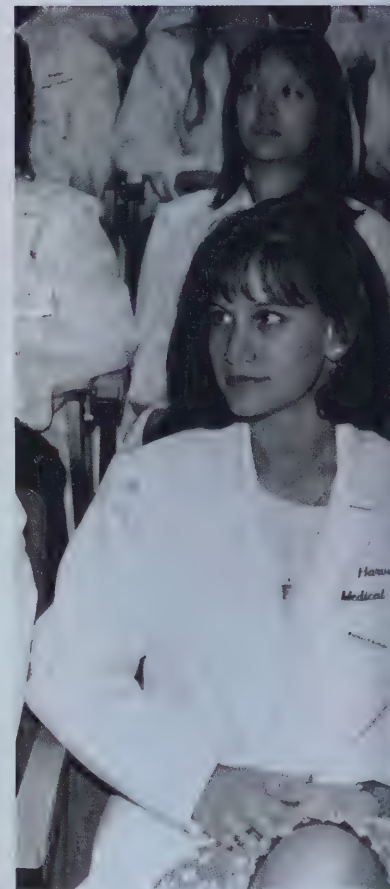
Meaningful relationships matter and are like crumbs cast upon the water that reap loaves of returns. 

Stewart L. Gilbert, MD '74, has retired from his internal medicine practice and continues to live in the Los Angeles area. This year, in honor of Bernard's fifty-fifth birthday, Gilbert sent him a blue and white birthday cake like the one they shared decades ago.

DETAILS, UPDATES, AND OBSERVATIONS FROM ALUMNI

What were your thoughts when you **first put on your white coat?**

White Coat Day is a day made for smiles, as in this photo of new student body president, LaShyra Nolen, a member of the Class of 2023, and a classmate at the August 2019 ceremony.



Alena Balasanova, MD '12

That my parents' sacrifice was worth it. They braved an escape from a war-torn country to seek political asylum in the United States to give their daughter a better life, one with opportunities that would allow her to grow up to be anything she wanted. For me, putting on that white coat was the embodiment of living the American dream. I am eternally grateful.

Steven Jonas, MD '62

That's my Class of 1962, and very proud of it!

Onesmo ole-Moiyoi, MD '72

I had worked very hard and felt I was on the verge of joining HMS to become an

HMS alumnus, despite many obstacles and, I should fairly add, many serendipitous opportunities, which I discussed in *Against All Odds* (pages 212-217) by Nora Nercessian, published by Harvard Medical School in 2004.

Robin Winkler Doroshow, MD '73

I wonder if they'll ever provide small women who are medical students with white coats that fit.

Paul Wheeler, MD '61

My thoughts focused on learning and on not making embarrassing mistakes.

Images from HMS Orientation Day, 1994: Aziz Maghen, DMD '99 (above, left) and Ann Bryant, MD '98; the Class of 1998 at an orientation lecture; and Richard Morris, MD '98 (far right).

John Mordes, MD '73

I do not recall, but I am certain, given the ongoing anguish of the Vietnam War at the time, that receiving the coat was not a big deal.

Luis Fernandez-Herlihy, MD '49

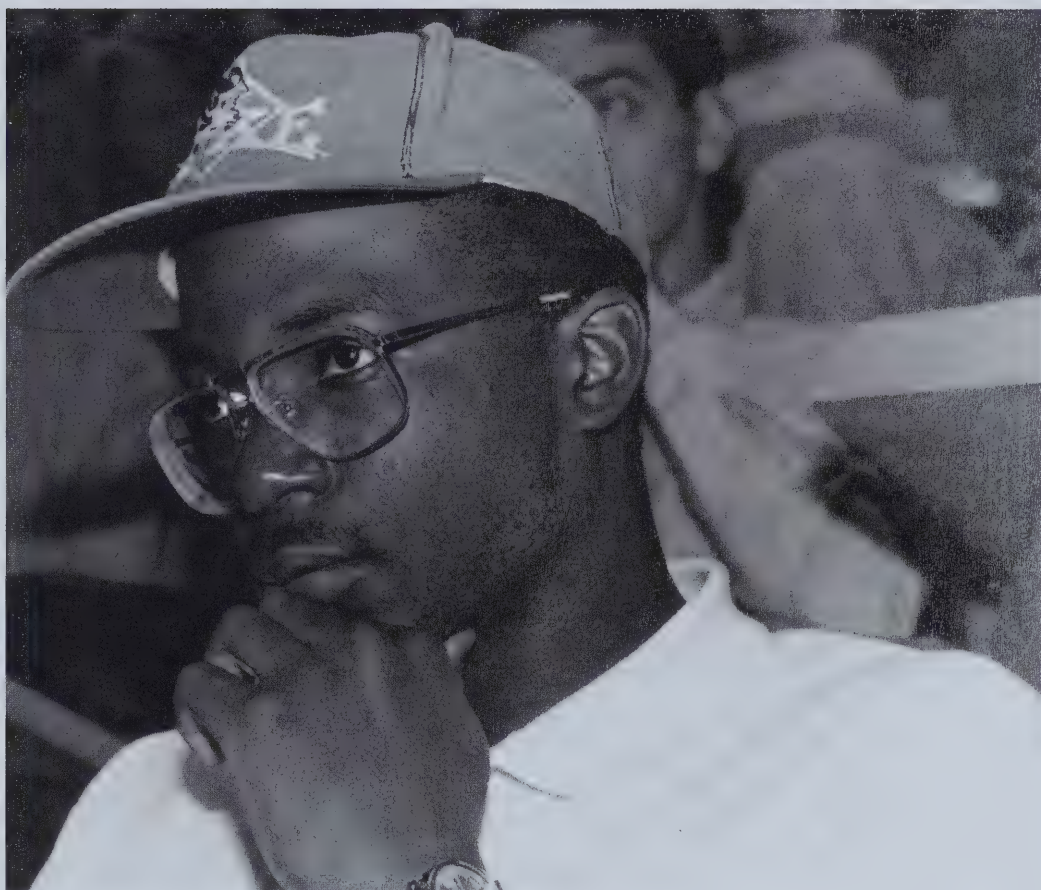
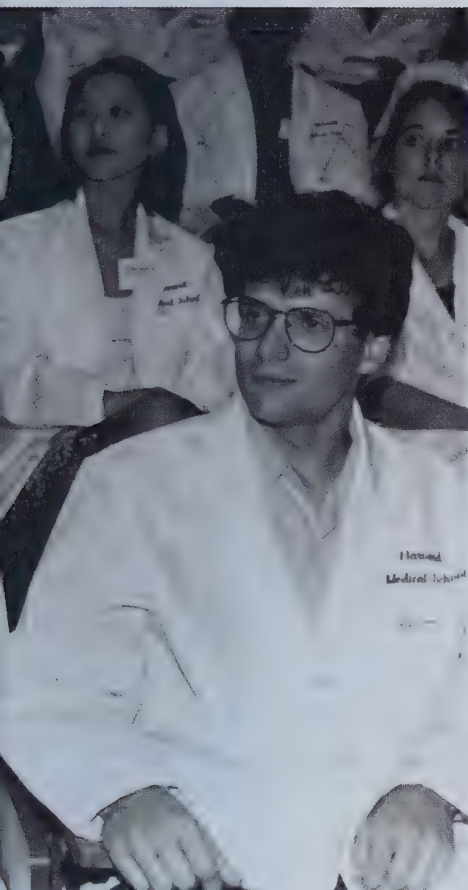
Awe, trepidation, and the pleasure of being able to relieve human suffering.

Hena Ahmed, MD '18

"What have I gotten myself into?"

David Dorsky, MD '82 PhD '82

When beginning ICM, to be honest, I was somewhat fearful that I wouldn't adapt well to being in the presence of illness or learn to treat it. Although interested, I was intimi-



dated. But the faculty were very supportive. I was lucky to speak with the remarkable **Oliver Cope, MD '28**, at Massachusetts General Hospital, and he gave me an autographed copy of his helpful book, *Man, Mind & Medicine: The Doctor's Education*, along with a copy of *The Science and Art of Medicine in Some of Their Aspects*, by **Fredrick Cheever Shattuck, MD 1873**.

Royce Moser Jr., MD '61

Hope I can learn to “care for the patient.”

Bartholomew Tortella, MD '80

The white coat physically brought home to me the responsibility of serving patients with all of my heart, for it is said that because

much has been given to you, much is certainly expected of you.

Samuel Kim, MD '62

Wow!

Carolyn Aldredge, MD '64

I thought, I am where I have always wanted to be.

Richard B. Dobrow, MD '62

I was excited to think that I had made a large first step toward becoming a doctor. We were able to wear name tags that said “Doctor,” which now appears not to be permitted in the interest of full disclosure to patients.

Joseph McCabe, MD '74

I thought, this is scary. I don't really know what I'm doing.

Donald Dillon, MD '59

I'm sure I felt altruistic, eager to fulfill a life-long desire to help people.

Carl Needy, MD '49

Pride.

John Merrifield, MD '59

I was 21, book smart, and scared. **John Stoeckle, MD '47**, took me in hand and, with firm mercy, saved my bacon.

Lloyd Hamilton, MD '54

As a corpsman with the U.S. Marines during World War II, I took care of many patients. My thoughts were the same then: How can I help this person with his/her suffering? It was a challenge.

Kaihi Fung, MD '82

I just felt great!

William Kupsky, MD '78

I thought, I'm not ready for this. It took years to get over the shock of being called doctor!

Richard Aadalen, MD '65

I felt proud.

Bruce P. Barnett, MD '75

While wearing the short white coat in medical school, I did not believe I had the knowledge or experience to be a safe and effective health care provider. The long coat I wore during residency did not make me any more confident.

John A. Stanley, MD '58

I cannot remember any significant thoughts or feeling.

Joseph Burnett, MD '58

Wow!

Mary Flowers, MD '78

Scary! I thought that I was important in making a difference in health care and society as a whole. I no longer wear white coats. I have not figured out what providers are supposed to wear.

Richard Peinert, MD '73

White coat? Wouldn't be caught dead in one! As a surgeon, I remember putting on scrubs in the locker room with **Francis Moore, MD '39**, talking to me and doing the same. I felt so very cool!

Tamara Fountain, MD '88

I look like a doctor! Fancy that.

“The white coat physically brought home to me the responsibility of serving patients with all of my heart, for it is said that because much has been given to you, much is certainly expected of you.”

George Ryan, MD '53

A pride of achievement, the happiness of family pride, and the feeling I had a lot yet to learn.

Roy C. A. Weatherley-White, MD '58

Pride and humility, if this is not a contradiction!

Joseph Barr, MD '60

We didn't get white coats until third year, or maybe until internship? Maybe we got name tags?

Hugh Hermann, MD '54

I was happy as hell.

Ernest Bergel, MD '56

I wondered whether I was worthy to wear it.

Samuel L. Katz, MD '52

Joy and pride in having achieved that stage of career development.

Richard Hirschhorn, MD '58

Pride.

Nathan Selden, MD '93

I wondered, will I do well? What will this be like? Will I make a difference? Will my patients value me, and my peers respect me? Medicine is fundamentally a voyage of humility.

Thanks to all who shared recollections of the moment they received their white coat.

The next issue of Harvard Medicine will carry your responses to the question: Did you play a musical instrument or sing while you were in medical school? Does music still have an important role in your life?

Responses can be submitted online: hms.harvard.edu/rounds; via email: hmsalum@hms.harvard.edu; by phone: 617-384-8520; or by mail: Rounds, Alumni Affairs and Development, Harvard Medical School, 401 Park Drive, Suite 505, Boston, MA 02215.

Obituaries

1940s

1943

Joseph T. Doyle, MD
June 18, 2019

1945

Edward A. Carr Jr., MD
November 8, 2019

Sidney C. Jackson, MD
February 13, 2017

1950s

1951

Robert G. Chapman, MD
July 16, 2019

Spinks H. Marsh, MD
October 20, 2019

Jack E. Tetirick, MD
August 26, 2019

1952

Mortimer Lorber, MD
September 8, 2019

1953

John A. Mannick, MD
October 13, 2019

Harvey D. Rothberg, MD
August 18, 2019

1954

Lloyd Hamilton, MD
November 9, 2019

1955

James Fife, MD
June 16, 2019

Donald O. Pollock, MD
September 29, 2019

1956

David U. Cookson, MD
August 7, 2019

Leon D. Sabath, MD
July 21, 2019

1957

Anna K. Wolff, MD
July 30, 2019

1958

Cecil H. Coggins, MD
September 19, 2019

Calvin J. Collins, MD
August 10, 2019

James Walker Wiggin, MD
October 12, 2019

1959

Gary W. Cage, MD
August 14, 2019

1960s

1960

Michael M. Frank, MD
August 1, 2019

Warren M. Russell, MD
October 27, 2019

Raphael F. Smith III, MD
July 29, 2019

1962

Guy B. Dewees III, MD
October 13, 2019

1963

George R. Babineau, MD
August 3, 2019

Harriet Kaufman Meiss, PhD
October 6, 2019

1964

Terry M. Bennett, MD
September 30, 2019

1967

Thomas P. Stossel, MD
September 29, 2019

Joerg C. Winterer, MD
July 30, 2019

1969

Peter J. Grillo, MD
August 6, 2019

1970s

1971

Robin I. Goodfellow, MD
August 26, 2019

1980s

1982

Vivian J. Woodard, MD
August 20, 2019

1990s

1995

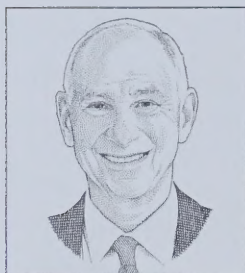
Sandra J. Downes, MD
July 24, 2019

This listing includes alumni whose notices of death were received between July 27 and December 1, 2019.



PRESIDENT'S REPORT

A Focus on the Future



THIS IS MY FIRST REPORT on the proceedings of the HMS Alumni Council. I am deeply honored to serve as president of the Council, and I am fortunate to follow the exemplary leadership shown by Lisa Henske, MD '85, during her tenure.

With a two-year term for the president, there is an opportunity to pursue ambitious initiatives. And, for the first time, the Council's deliberations are informed by the addition of two medical students: the co-presidents of the fourth-year class.

I have asked the Council to focus on one major project and only a few small ones for the next one to two years. We have

placed financial aid at the top of our agenda. There are several reasons for this, including that the financial burden of attending HMS and other private schools has increased dramatically over the years; that growing student debt may be distorting medical student career choices; and that debt burdens can affect the future well-being of medical families, especially when there are two debt-carrying physicians.

Recently, several prominent medical schools, after receiving nine-figure donations, have transformed their approach to financial aid. The media has shined a spotlight on these schools and on the larger issue of medical-student debt. One school is now tuition-free for all. Other schools have eliminated student debt entirely. Still others, in an effort to attract students from competitors, are deploying scholarships without linkage to financial need.

While HMS' financial aid program is both generous and need-based, the School's leadership is actively reviewing its philosophy around such support. Should tuition-free be an aspiration, or does a debt-free approach specifically for those in need fit better with HMS values? Or is it wise for students to have "skin in the game" in the form of some level of debt? If so, would this be equitable, or would it deter qualified students whose families have limited means? Should alumni direct their gifts to student financial aid?

The Alumni Council is ready to work with Dean George Q. Daley, MD '91, and Dean for Medical Education Edward Hundert, MD '84, to provide counsel on these questions, review messaging around our aid packages, and help obtain resources. From the perspective of philanthropic support, no group is more interested in supporting students than the alumni.

Student debt is a complicated and pressing matter that will require much bandwidth to address. But there is also room for the Council to work on other matters. Several topics are under consideration; I encourage alumni to send suggestions now while we are still prioritizing the Council's efforts for the coming term.

We look forward to hearing from you.

Michael Rosenblatt, MD '73, is the chief medical officer at Flagship Pioneering in Cambridge, Massachusetts.

Alumni Announcements

Alumni Cocktail Reception in Philadelphia

Meet and greet local alumni at an informal cocktail gathering on Wednesday, February 5, from 5:30 to 7:30 p.m. in the Thomson Gallery at The College of Physicians of Philadelphia. HMS Dean for Medical Education Edward M. Hundert, MD '84, will give brief remarks about the future of medicine and answer questions about HMS. To RSVP or for more information, call 617-384-8520 or email

hmsalum@hms.harvard.edu.

Reunion

Alumni from classes ending in 0 or 5 and their guests are invited to rediscover campus and rekindle friendships during 2020 Reunion festivities, June 4–6.

Among the many events being planned are a gala, faculty and alumni symposia, class-specific events, and a family picnic with a cookout and games. Visit alumni.hms.harvard.edu/reunion for details. Registration opens in March.

Alumni Day

Reconnect with fellow MD alumni, learn about current events at the School, and hear about the future of medicine. It all happens on Alumni Day, June 5. Program highlights include the dean's State of the School Address, the Harvard Medical Alumni Association's annual business meeting, the Alumni Day Symposium, and campus tours. Members of the Society of the Silver Stethoscope—alumni who have celebrated their 60th reunion—are also invited to a private lunch. Visit alumni.hms.harvard.edu/alumni-day for the latest details.

Distinguished Service Award for HMS Alumni

The winner of the 2020 award, which recognizes and celebrates individuals who have demonstrated loyalty, service, and commitment to HMS, will be announced during the Harvard Medical Alumni Association's annual business meeting on June 5. Learn more about the award and nominate an HMS alumna/us for 2021 at alumni.hms.harvard.edu/service-award.

Harvard Alumni Directory

Are you interested in finding and networking with fellow Harvard alumni? Look no further than the Harvard Alumni Directory. Graduation from HMS makes you a member of the Harvard Alumni Association, and the alumni directory is one of the benefits you receive as a member. You can use the online directory to search for alumni by industry, region, specialty, class year, and more. Visit community.alumni.harvard.edu.

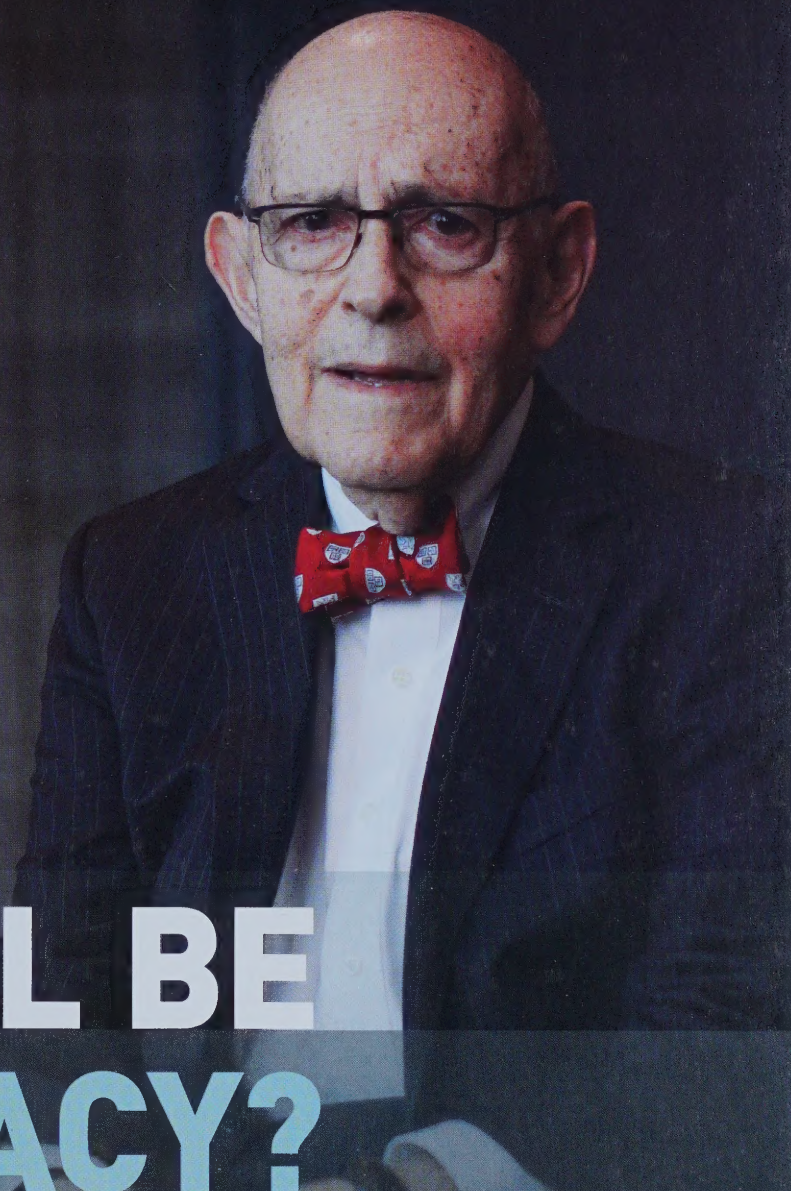


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— Mitchell T. Rabkin, AB '51, MD '55

*CEO Emeritus
Beth Israel Deaconess Medical Center*



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Mitchell T. Rabkin has spent nearly 70 years as a member of the Harvard Medicine community, as a student, researcher, teacher, mentor, and hospital CEO. By naming HMS in his estate plan, he is also ensuring he makes a lasting impact.

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Hemmed In

The expectation of rejection and discrimination experienced by members of the LGBTQ community can contribute to stress and mental health issues such as anxiety, depression, and suicidal ideation.